



SANCHAR — An experience of community-based Rehabilitation of Disability

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A Society for Appropriate Rehabilitation of the Disabled
Santi Tuberculosis Control Society Campus

Vill. & P.O. Pailan, Via-Joka, 24 Pgs. (S), Pin-743 512, West Bengal, INDIA

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We would like to thank

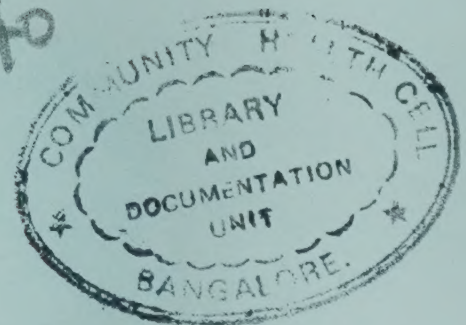
- * MIBLOU, for their understanding, encouragement and support in everything we have done.
- * UNICEF, for their support in the preparation of this document.
- * The children with whom we work, and their families, for helping us to learn and grow,

and

All our friends.

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INTRODUCTION

Our organisation is now barely five years old. We are a small team of seven persons working in 30 villages of South 24-Parganas district of West Bengal. We started working with the conviction that persons with disability can act to change their own lives and situations, and have the potential of becoming members of the community on equal terms with everyone else. This was not a new concept in the field of disability - since 1981, approaches focussing on empowerment of persons with disability, and using and building on existing community resources, were being actively promoted by international agencies. However, there seemed to be an infinite number of variations in how these objectives could be achieved. We, and many others like us, have been trying through our work, to understand how the basic values and philosophy of people-centered and people-controlled development can be actualised to help persons with disability become active initiators of, and participants in change processes in society.

In the last four years, we and the people we work with have learnt and grown. In the process, we feel that we have moved a considerable distance from where we started, and, to a large extent, have "made the road by walking". We felt the need to stop and look back - at what we wanted to do, what we have done and how we have done it. We wanted to find the answers to some basic questions - what did we believe when we started? Do we still have the same beliefs and values? Have our experiences strengthened our earlier understanding of our objectives? Have our strategies been effective? How do we need to change them?

We have attempted to work together to find the answers to these questions, and build on them to plan for the next phase of our work. Over the last year, we have been going through a series of exercises designed to help us to recall, reflect on and analyse our work. We created space for this process within our normal work - at our weekly group meetings and at two workshops away from our place of work, where we could concentrate exclusively and intensively on the objectives we had set for ourselves :

- to examine our own learning and understanding about our work over the past years;
- to re-evaluate our objectives and strategies, and reach a common understanding of these;
- to plan our work for the next 4-5 years; and
- to document our growth and development for ourselves as well as for sharing with others.

When we started work as a separate organisation, our team consisted of four people with widely different backgrounds and experiences. Three more of us joined at later stages. It is our belief that we, as individuals with our strengths and weaknesses, have been crucial to the way in which our organisation has developed. Our work has evolved in its own unique manner because of the varied ways in which we have each contributed to it. Of the seven of us, only one person has formal academic training in working with disability (he is a qualified physiotherapist). The rest of us have learnt by doing, and one person has recently qualified as a teacher of the deaf. Three of us who joined the team later had no previous experience of working with disability, although the core group which started the organisation had previous experience ranging from 4 - 13 years in various settings and programmes. In our own way, we are a good example with which to counter the idea that disability is a medical or technical issue.

In Chapter I, we have tried to look at how and why we started working the way we did, and our initial understanding of an alternative strategy. Chapter II describes our early experiences of getting to know the community and starting work. Chapter III is an account of our activities, structures and system at present. Chapter IV documents our major insights and our understanding of issues. In Chapter V we have tried to look at the strategic implications of working towards an integrated approach.

We hope this document will help others who are working or want to work with disability. We would appreciate comments and feedback from readers.

November, 1993.

'SANCHAR' team.

Chapter - I

BACKGROUND : LOOKING FOR AN ALTERNATIVE STRATEGY

The initial idea of starting a community-based programme of our own grew out of our various experiences of working in institutional settings, mainly with children who had movement problems. After undergoing corrective surgery, these children generally spend extended periods in a hospital or centre for fitting of appliances and training in how to use them, physiotherapy and follow-up care. It was fairly usual to see children from remote villages blossoming in the atmosphere of these institutions, with their facilities for education, play and interaction with other children. When the time came to go home - that is, when they were judged to be rehabilitated - these children would often refuse to leave. The reverse was also common - many parents, for whom the problems of looking after a child with disability were compounded by poverty, preferred to "abandon" the child in a place where care, education and a future seemed to be assured. Repeated encounters with this kind of situation began forcing us to question the validity of our rehabilitation strategies. What did 'rehabilitation' mean? If we were trying to help children to lead normal lives, then who would set the standards for what was normal - we ourselves, or the child's parents and community? Could we, as rehabilitation workers, take on a long-term commitment to ensuring a future for the child? Were our efforts at rehabilitation actually making it more difficult for the child to become integrated in the community?

These were questions that occurred to many others involved in rehabilitation work. One solution was to have an 'outreach programme', or a 'community-based' programme. These programmes are usually run as a supplementary community-based activity, by institutions which already have centre-based rehabilitation facilities. In our experience, this kind of programme was designed to fulfil several objectives. First, it could increase awareness about disability in the community, resulting in prevention of childhood disability, and as well as ensure intervention as soon as possible after the event in cases where the

child did become disabled. In addition, community-level clinics set up under the programme would make up to some degree for the limited facilities at the centre, which fell short of the demand. It was also expected that a pool of knowledge would be created in the community, and that parents and members of the family could be given training in carrying out interventions.

However, in practice, we found that in such "outreach" programmes, the involvement of the community was often restricted to providing venues for meetings and community clinics. Although there was some impact in terms of prevention of disability and early intervention, little could be done for children who were already disabled. In most cases, referral to existing government hospitals and medical facilities other than the centre running the programmes have not resulted in any sustained intervention. Community clinics are held infrequently, the training given to parents is inadequate to build their competence to the required level, and there is no regular follow-up. Many outreach programmes do not continue if external funding and support are withdrawn.

The label of community-based rehabilitation (CBR) was one that was taken up and promoted by the WHO. In 1981, the WHO defined CBR as an approach which "involves, utilises and builds on existing resources in disabled persons themselves, their families and communities". Much time and effort was being put into exploring the parameters of this strategy in various situations. The CBR approach was also considered the appropriate approach in developing countries, parallel to the primary health care concept. Several factors were being cited in favour of adopting such an approach. These included :

- * Lower costs
- * Wider accessibility and coverage
- * Community involvement leading to permanent change.

When we first started thinking of working on our own, we tried to articulate our understanding of disability and rehabilitation. It appeared to us that the main problem faced by persons with disability was their low self-esteem. Their own awareness of being unlike others, and unable to do many things that others could do with ease, of being dependent on parents and families for survival, led to feelings of uselessness which were compounded by the attitudes of families and communities. Even otherwise concerned and caring parents referred to their children as "the blind one", or "the dummy" or "the idiot". The "professional" approach to disability had, we realised, gradually trained people like us to look at it as just a medical problem, which could be solved by a set of standard interventions, even when the evidence - such as our experiences in centres and outreach programmes - showed that the problem involved the person's entire existence. We felt that the abilities and potential of the person, which could provide a foundation for life as a member of the community, were being neutralised and downplayed by many of our interventions. We began to use the terms "persons with disability" or "child with disability" instead of the more usual "disabled child" or "disabled persons", to remind us that the individual, and not the disability, was central to the issue.

We were able to articulate some of the features of the alternative approach we were planning to implement.

- * We would work from the understanding that disability is a developmental issue rather than a technical one. Community-based rehabilitation therefore involves more than rehabilitation efforts carried out at the community level. Rather, it encompasses other processes through which people become empowered to take control of their own lives and situations. In this perspective, CBR is an educational intervention which has the potential to facilitate and strengthen other social change processes.

- * In line with our faith in conscious and collective action as the fundamental force for change, our work would focus on helping people with disability, their families and communities to work collectively to identify and analyse their problems and plan and implement strategies to deal with their situations.
- * We saw our role as being one of initiating and sustaining a process of capacity-building for children with disabilities and their families, with any services we could provide being contributory to this process.
- * We would use local resources available to the community to provide necessary services. As far as possible, we would utilise existing services and facilities.
- * We planned to involve children, their families and the community in all our activities from the very beginning and at every stage, to build a genuine partnership rather than a relationship of dependency.

A strong motivating factor in our decision to try and actualise our understanding of CBR was the encouragement and support we received from CINI-Child In Need Institute. This NGO works in some 40 villages in South 24-Parganas district of West Bengal. The focus is on mother and child health, through community action using the platform of a network of village-level women's groups. Our partnership with CINI started with a survey of existing facilities for the disabled in the State. The results of this survey were published as a Directory in 1988.

By the beginning of 1989, we began to seriously consider the possibility of working in the same villages as CINI did. One of the main reasons was the presence of CINI's Mahila Mandals, or village-level women's organisations. We felt strongly that these groups, with

a certain level of organisation and commitment to community development, as well as previous experience of collective action, could become our platform for raising the issue of disability. However, we first had to find out whether the disability situation in the area needed or justified an intervention of the kind we were thinking of with the following objectives :

1. Initiating community-based rehabilitation services for children with disability in the area, helping them to become independent and self-reliant.
2. Extending support to other organisations working or planning to work with the disabled.

Chapter - II

GETTING TO KNOW THE COMMUNITY : THE INITIAL PHASE

As our first step to getting an idea of the situation of children with disabilities in the CINI field area, we had decided against conducting a house-to house survey. We had a number of reasons for this desision.

1. Our experience with surveys in our earlier work had shown that they are expensive and time-consuming, especially for a small team like ours.
2. With so many NGO's and governmental agencies targeting people for development, many communities automatically think of surveys as mechanisms for identification of "beneficiaries". Surveys therefore often raise unreal expectations about forthcoming material gains, and can result in bitterness and frustration if these expectations are not met.
3. Many parents may find it painful to discuss sensitive issues such as disability with strangers, especially when they are not sure what the outcome will be, or how it will benefit their children.
4. In villages, unlike urban communities, people living in the same neighbourhood know each other and their families well. We felt that information on children with disabilities would reach us from many sources once it was known what we were doing.

We decided to capitalise on existing community resources, the Mahila Mandals and CINI village health workers, to make the process of survey a tool for getting to know the community and building a partnership with them.

Looking back, our field workers recall that when we started meeting Mahila Mandals and moving in the villages with CINI health workers, we had no definite idea that we would be working in the same area. At first, we thought of this activity as a preliminary exercise. After a period of getting to know each of the team of health workers, and becoming familiar with their work, we began collecting information from them about the families of children with disability in each of the villages. Since each health worker had comprehensive records of families in her area, we did not anticipate any problems. However, this turned out to be a very simplistic expectation. Since many cases of disability were 'invisible' to the community - either because they were considered beyond hope, or because they were not identified as a disability at all - we found that even after a six-month period, we had lists for only 20 out of the the 40 villages. Also, since disability was not one of their priorities, CINI's records were not complete. Disability was listed under the category of "chronic illness" without any other specific details. However, by this time we had built a good relationship with the health workers and had been making visits with them to homes where a child with disability had been located.

At this time, the villages where CINI was working were being divided into two clusters on the basis of the level of functioning of the Mahila Mandals. The Mahila Mandals in 20 villages had been identified by CINI as being active and effective. We decided to start by working with these groups. Initially, we would attend the bimonthly meetings where the CINI health worker for the village would sit with the members of the Mahila Mandal to discuss and plan various activities, ranging from sponsorship of children from disadvantaged families, to day-to-day management of health camps and preschools run by the group, and the work of community health promoters. The health workers would introduce us to the members of the group, and we would explain what we were doing and planned to do. Members of the group, balwadi teachers and health promoters soon began taking us to homes where a child with disability had been missed out by the CINI worker, and introducing us to the families.

As we had expected, once word got around that we were meeting families with a child or children who were disabled, several people came to us when we visited the villages, to tell us about a relative, neighbour or acquaintance who had a child with disability. Some of the most reliable informants were children, who would escort us to the home in question and introduce us to the family. Other sources were people we met and talked to at the village tea shop, where the men generally gather for a daily chat. Later, as we became familiar with more and more people, families would come and invite us to visit them and have a look at an adult or child who was disabled in some way. Often, these families were from villages other than those where we had decided to work.

Families and their situations

Most of the families we visited were very poor. Most were employed as agricultural workers, or as workers in small local industries. Women, apart from housework, were usually also engaged in some kind of paid work, either in agriculture or in weaving mats, 'biri' - making or taking orders for needlework from tailors. The majority of adults had little or no formal education, and many women were illiterate. However, most families sent their children to the balwadis run by the Mahila Mandals.

We found that, in the majority of cases, the parents of children with disability had gone through an initial phase of seeking help for the child. The nature of this help depended to a large extent on the economic circumstances of the family, the extent to which the parents were aware of various options, and the resources available in the area. In the case of children with problems of mobility, most had been taken for surgery and appliances. Some of these children were attending normal schools, and we hardly considered them disabled even though most had discarded their appliances. The parents of children with hearing handicaps, mental retardation, cerebral palsy and other multiple disabilities had all spent varying amounts of time and resources in looking for a 'cure' for the child's condition. These

ranged from making the rounds of hospitals and clinics, to quack doctors, traditional healers and holy men, and putting the child through various 'treatments'. It was only after prolonged 'treatments' with no result that parents gave up and became resigned to the fact that their child was never going to be like other children. Many parents were left with the feeling that they had not been able to afford the right kind of treatment. We found that most of the children with hearing disabilities had their own ways of communicating with their families and, except for not going to school, led lives very much like other children in the community. However, children who were mentally handicapped, had cerebral palsy or multiple disabilities were often thought of as burdens by their families. In most of these cases, the child's condition was thought to be the result of divine punishment. The primary concern of the parents was the child's future when they were no longer able to provide constant care, but few saw any alternative to leaving things to fate.



We would start by introducing ourselves to the family and explaining what we wanted to do. Reactions were varied. Some parents assumed that we were part of CINI's child sponsorship activities, and would be able to arrange for the child's treatment as well as provide financial support to the family. Others were sceptical about the child's capabilities. Still others were interested and immediately enthusiastic.

When the family accepted that we were genuinely interested in working with them to help the child, we would begin the process of together analysing the child's present situations and problems.

What did they feel was the cause of the disability ? When had they first begun to notice that something was wrong ? What had they tried to do ? What was their assessment of the child's present condition - better than before ? Or worse ? What were the problems they were facing ? What were their concerns for the future ? What were their expectations for the child ? During these interactions, often spread over months, we would make friends with the child and others in the family, and share our experiences in working with children in similar situations. Our relationship was being built on a mutual understanding of what we could each contribute to bringing about change in the situation of the child.

The first and often most difficult step was to help the parents and the child to accept that the disability was a permanent one, and that there was no cure, no medicine or treatment that would make the child "normal". It was only after this understanding was reached that we would move to a critical appraisal of the child's problems and potentials. Based on this analysis, and on the basis of the expectations and needs of the child and family, an individual learning programme could be worked out for each child. This programme became our work plan, to be implemented in the child's home, in partnership with the parents.

As we interacted with more and more families, we realised that acceptance of the fact that the child was permanently disabled was seldom a "once and for all" event. Very often, both the child and the family would, having reached this acceptance, start on a programme of learning, when something - information about a miracle cure by a holy man, a chance remark from a neighbour or relative, a period where progress was almost invisible - would once again set off a search for "treatment". Sometimes, we would be resented because we seemed to be presenting a gloomy and discouraging picture. The child's learning programme would come to a halt while we went through a fresh process of explaining the cause for the child's condition and helped the parents to understand the implications. Of course, some parents struck to their original explanation for the child's

condition - a curse, or punishment for a sin. We realised that this was the way in which they were trying to cope, and tried to respect these feelings where they did not harm the progress of the child.

Sometimes, some extraordinary progress made by the child could also spark off a false sense of optimism in the parents, who would again build expectations of a 'cure'.

Many of these feelings of despair and optimism at some points in our interaction with the child, were experienced by us also. It was thus easier for us to understand and respect the parents feelings.

In late 1989, we started individual learning programmes with a handful of children. In the next two years, our interventions grew to cover 30 villages and 154 children. The following Tables will give an idea of the children we work with.

Field Area : (For the period April 1992 to March 1993)

1.	No. of Villages	:	30
2.	No. of Families	:	148
3.	No. of Children	:	154

1. Work with children in field area : Individual Package Programmes (IPP)

Sl. No.	Nature of Disability	Locomotor	Vision	Hearing	M.R.	Multi-ple	Others
1.	Number of children detected	62	2	33	26	30	1
2.	Number of children under IPP		x	24	19	16	
3.	Number of children showing progress (IPP)		x	20	14	12	
4.	Number of children still under assessment		x		1	x	
5.	Number of children being followed-up (no IPP)	52	2	4	2	8	1

2. Gender distribution of children with disability in field area

Sl. No.	Nature of Disability	Boys	Girls	Total
1.	Locomotor	40	22	62
2.	Multiple	19	11	30
3.	M. R.	14	12	26
4.	Hearing	17	16	33
5.	Vision	2	x	2
6.	Others	1	x	1

3. Age distribution of children with disability in field area

Sl. No.	Nature of Disability	0 - 5 years	5 - 10 years	10 - 15 years	15+ years	Total years
1.	Locomotor	13	20	24	5	62
2.	Multiple	6	11	10	3	30
3.	M. R.	1	10	13	2	26
4.	Hearing	3	9	17	4	33
5.	Visual	x	x	2	x	2
6.	Others	x	x	1	x	1

4. Income status of families of children with disability in field area

Sl. No.	Nature of Disability	Below Rs.250	Rs.250-500	Rs.500-1000	Rs.1000-1500	Rs.1500+
1.	Locomotor	3	23	26	9	1
2.	Multiple	2	8	13	1	6
3.	M. R.	x	6	10	3	7
4.	Hearing	x	12	9	6	6
5.	Visual	x	2	x	x	x
6.	Others(Fits)	6	x	x	x	x
Total		6	51	58	19	20

5. Educational status of children with disability in field area

Sl. No.	Nature of Disability	School Going	Non-School Going	Functional Literacy under IPP	
				School Going	Non-School Going
1.	Locomotor	28	34	x	x
2.	Multiple	2	28	x	x
3.	M. R.	2	24	x	x
4.	Hearing	3	30	3	21
5.	Visual	1	1	x	x
6.	Others	1	x	x	x

6. Work with children in field area : Follow-up for children not under IPP (Locomotor Disability)

Sl. No.	Nature of Disability	Children referred for		Children managing well after surgery and/or aids	Children not referred but managing well
		Surgery	Aids		
1.	Polio	2	x	6	2
2.	CTEV	3	2	4	x
3.	CDH	x	x	x	x
4.	CDP	x	x	x	x
5.	Arthrogryphosis	x	x	1	x
6.	Myopathy	x	x	1	1
7.	Hemiplegia	x	x	x	x
8.	Phocomalia	x	1	1	x
9.	Amputee	x	x	x	x
10.	Others	x	x	1	3
Total		5	3	14	6

7. Children with disability attending CINI Under-5 Clinic

Sl. No.	Nature of Disability	No. of Cases Seen	No. of Referrals	No. of Follow-ups
1.	Locomotor	57	26	9
2.	Multiple	35	2	17
3.	Hearing	3	1	x
4.	Others	31	8	8
5.	M. R.	5	x	x
Total		131	37	34

Our experiences with Swapna and her parents are typical of the way in which, through a series of interactions, our partnership with the parents grows and develops.

When we first met her, Swapna was 10 years old. The oldest of four children. Swapna is severely spastic. The family is comparatively 'well off' - they live in a two-room mud hut on their own land, have some agricultural land and a fishpond. Apart from this, Swapna's father occasionally operates an illicit country-liquor still. Although, when we first met him, Swapna's father estimated his monthly income at about Rs.600/-, we found that he was able to employ labourers both to farm his land and run the distillery. He himself was the kind of person who sat at his ease and ordered others around, at home as well as at work. As for Swapna's mother, she was always busy around the house - in all the time we have known her, we have never once seen her resting or relaxing.



Swapna's mother told us that, for a week after she was born, Swapna ran a very high fever. When the baby was a year old, her mother realised that she was not able to sit up by herself. She was taken to a doctor who told the parents that she would be able to walk at the age of twelve. A series of visits to other doctors and hospitals followed, with no improvement in the child's condition. Finally, the family gave up hope. When we met her, Swapna spent most of her time lying on a mat on the veranda of their house. She was able to drag herself, or roll around on this veranda, and sit for some time if she had something to lean against, but with great difficulty. She could feed herself with her left hand while lying on her side. She had bowel and bladder control, her hearing was normal and she could speak well enough to be understood, although in a slurred way.

Swapna, we soon realised, was an exceptionally intelligent child. She understood and deeply resented the fact that she was unlike other children, and that many people reacted to her with pity or distaste. She felt that her parents thought of her as a burden, and would 'punish' them for this attitude in various subtle ways, like complaining about them to us, and spending as much of her time as possible with her maternal grandparents who lived nearby. Her grandparents, especially her grandfather, doted on Swapna and did everything they could to spoil her. Swapna had something of a royalty syndrome, and insisted on having everything being done for her. She would refuse to make an effort to help herself and was demanding and bad-tempered most of the time.

Many of Swapna's feelings of dissatisfaction and depression came from her sense of being deprived of many things - being 'normal', being rich, living in a city, having an exciting life like girls of her age in the video films she watched at the village video parlour. Swapna told us that her parents thought her a useless burden, that they would be happy if she died. We put the situation to her as a challenge - we told her that she would have to convince her parents that she was capable of doing a lot. We would help her, but the main job would be hers.

Initially Swapna's father was very aloof and distant with us. His attitude seemed to be that nothing could be done with the child, but we were welcome to try. On most of our visits, we would find Swapna at her grandparents', and it was the grandfather who initially became our friend and partner. Swapna was a fast learner and was soon bathing herself, as well as dressing and undressing on her own. We decided that she could learn how to sweep the house. Her grandfather made a special small broom for her and she started learning to use it while walking on her knees. Swapna was, however, adamant on one point - she would sweep her grandparents' house, but not her own !

Since Swapna found it very difficult to sit up on her own without support, we decided to make a chair for her with a backrest and a kind of table in front. Although Swapna's father was an interested observer during our discussions about the design of the chair, it was her grandfather who had most of the ideas. However, Swapna's father got together the materials required to construct the chair - something which gave us hope that his attitude was changing.

Swapna's father now began taking more interest in us and our activities. He was curious and would bombard us with questions - did we all have college degrees ? How much did we earn ? Did we have contacts with the government ? Could we arrange for some 'grant' for the child or an allowance for the family ? He and his wife had initially wanted to put Swapna in a Home where she would be looked after, but when he saw how much Swapna had learnt and changed, he began to feel interested in her as a person. Swapna's mother began to ask her to help with simple chores like cleaning rice or sorting vegetables, and praising her for being able to bathe and dry herself, dress and undress, and get on and off the veranda steps on her own. Swapna began to feel proud of her achievements and told us she wanted to learn to read and write. She struggled to learn how to hold a pen and was soon writing her name and doing simple sums.

Now, when we visited the house, Swapna's father would come and watch the exercises we helped Swapna to do to release the spasticity in her limbs and to help her to use them. We had been talking for months about making a table for Swapna, at which she would be able to sit and eat. Swapna's father would keep promising to get together the required materials, but kept 'forgetting'. Finally, more than a year later, we found that a table had appeared - Swapna's father had hired a carpenter and spent a considerable amount of money to get it built. Now, when we told Swapna that her parents loved her and cared about her, she responded with smiles and not her former scepticism.



Things were changing - Swapna's father badgered us into getting a wheelchair for her in which he himself would wheel her to her grandparents. Her mother was brighter and more open to us, and was teaching Swapna to mop the floor. We had discussions with her parents and grandparents about what Swapna could do to earn her own living when she was older - the idea of a small poultry farm was mooted. Swapna herself was a different person - cheerful, confident and eager to learn and do more and more.

One day, about a year ago now, Swapna's father told us that her grandfather had met a man who promised to cure Swapna and make her walk after a massage with holy oil. To our dismay, we found Swapna quite convinced that she was going to be like other children - she told us that she would only do the work she chose, bringing water and sweeping the house after she was "well". Once again, we spent many hours with Swapna's parents and grandparents going over the situation. Swapna's mother told us that she was back to her old self - sulking and refusing to do anything for herself. We all sat together and talked to Swapna, and helped her to understand that if she did not do things for herself, she would never be able to learn, and that she had to take responsibility for herself. It was painful for us all, most of all for Swapna, to think that one day she would be left alone, with no parents to look after her, and how she managed then depended on her making an effort now. Swapna agreed, although reluctantly, to learn new skills and struggle to become self-sufficient.

Chapter - III

'SANCHAR TODAY' : ACTIVITIES, STRUCTURES AND SYSTEMS

From our initial interventions with a handful of families, we have grown today to working with 154 children and their families in 30 villages, in two Blocks of South 24-Parganas district in West Bengal. This is a predominantly agricultural district, but our area falls on the fringes of the semi-urban belt surrounding Calcutta. Much of the agricultural land is being bought up by developers and the city is gradually encroaching on the lives of people in these villages. Literacy rates are low (56% for men, 33% for women according to the 1991 census). Our activities fall into the two broad areas of field programmes and support programmes.

1. Field programmes

The thirty villages where we work are spread out on either side of a trunk road, with the furthest being 30 kilometers away. Five members of our team are involved in the field programme, which is their primary activity. When we started, we walked or took buses whenever possible, or cycled to the villages. However, our field area is so spread out that we found that most of our time went in travelling. We now use motorcycles for transport, and each member of the field team visits an average of 4 - 5 children everyday, five to six days a week for intensive programmes, apart from follow-up. Each child is visited at least once a week, usually by one particular worker, although the family is also acquainted with the rest of us. This tagging of child and worker has been done mainly on a geographical basis, so that time is used more efficiently. Each worker does not necessarily handle the same number of children. We are not 'specialised', in the sense that each of us handles children with different kinds of disability - locomotor, hearing handicap, mental handicap, cerebral palsy with multiple disabilities, visual impairment and some others.

Our intervention in cases of children with disability consists of working in partnership with the parents and family of the child to design and implement an individual learning programme for each child. Basically, we follow the pattern of working developed in our initial year in the field.

- For the first months after being introduced to the family, we focus on building a relationship with the child, the parents and others in the household. We try to help the parents understand and accept that there is no possibility of a complete and permanent 'cure'.
- This understanding is then the basis of a realistic appraisal and analysis of the child's situation, potentials and problems in becoming a member of the family unit on equal terms with everybody else. We try to help the parents and family to conceptualise and describe their own knowledge of the child's condition, and the attitudes, adaptations and problems resulting from it. This is also a learning process for us, as it helps us to get an idea of what is 'normal' in the context of that particular family, and what the parents expect in terms of their own and others' relationship with the child.
- Next, we, as persons with some experience in working with disability, are able to present a range of options and strategies which are possible. Together, we examine each option for its appropriateness, cost-benefit ratio and feasibility in terms of available resources. Our focus is on helping the parents and family acquire the confidence to make necessary decisions, on the basis of a complete understanding of the situation.
- Based on this analysis, and depending on the child's abilities and condition as well as the parents expectations and priorities, we then work out an action plan for the child.

- Activities and programmes in line with the objectives of the action plan are implemented in the child's home, in partnership with the parents. During our weekly visits to the child's home, we review and assess the child's progress and carry out a learning session. On the other days of the week, the child's parents or another member of the family continues the 'lessons'. Our experience with Bishu gives an idea of the process.

Bishu's was one of the first families we visited when we started going to the field in 1988. Bishu was then 10 years old. It was a large family - the parents, three sons (one of them married, with a child) and two daughters. Bishu's father owns some land and a part-share in a fishpond, and both his brothers work in a soap factory. His father and one of the brothers had studied in school for some years, but his mother is illiterate. Bishu's sister-in-law has studied up to Class-V.

When we first met him, Bishu was going to school (he was in Class-II). He was profoundly deaf and did not speak. He was having trouble in school. His father complained that he did not study. His sister-in-law, who sometimes tried to teach him his lessons, complained that he would not sit at his books for longer than a few minutes.

Over some visits, and long chats with his parents and sister-in-law, we got to know more about Bishu. His mother told us that he was a normal baby, but, after a series of severe fits when he was 1½ years old, had become deaf. His parents had taken him to a hospital, where a hearing aid was prescribed, but Bishu's father did not like the idea, and the aid was never bought.

We talked to Bishu's parents about their son's disability and explained that he literally lived in a silent world. His problems at school and his inattention with lessons was a function of this, rather than any disinclination to study. We also discussed the pros and cons of hearing aids.

Bishu's main problem, according to his parents was that, although he could communicate with his family and understand some of what others were saying, he could not make himself understood to outsiders. He was already doing daily-paid agricultural labour working in the village, and, although he could recognise the value of individual notes and coins, he could not add, and so at times came back in the evenings with a handful of loose change which was short of what he should have been paid. Apart from this, Bishu was like any other child in the village - he helped with chores around the house, played with his friends and was well able to look after himself.

Soon after we had started visiting him, Bishu dropped out of school. He was, by now, a good friend, and looked forward to our visits and playing with us. His family agreed that if he could be taught to read, write and count, he would have no problems in leading a normal life.

One option was to take Bishu back to school, and speak to the teacher about special help for him. The other was to take up the job ourselves. His family and we agreed that the chances of getting special inputs in the village school, where the single teacher was already overworked, were poor. We had no previous experience in teaching, but we decided on a programme of functional literacy for Bishu, alongwith teaching him to communicate better through a combination of writing, signing and lip-reading.

We now prepared the learning plan. Our targets for the first year were to teach Bishu to :

- count from 1 - 50
- to learn to write the names of his parents, his village and the things he saw around him every day (tree, mango, house, cycle, shirt, rice and so on)
- to learn to add money.

For the first three months, our targets for Bishu were :

- recognising 5 words
- writing all the letters of the alphabet
- recognising coins.



We worked out how these objectives could be achieved. We started with cards with the picture of the object and the word naming it. Bishu would play with these cards and try to match words and pictures. He already had some practice at writing the letters of the alphabet in school, but now progressed to recognising specific letters in the words written on the cards. For counting, he would put the right number of tamarind seeds beside each of the coins we showed him. Bishu's father and sister-in-law would sit with us on our weekly visits and watch what we were doing. His sister-in-law would make him practice with the cards and seeds every evening and soon, at every visit,

we could start with a new word, letter or coin. After 3 months, we were able to set fresh targets for the next 3 months.

Over the next 3 years, we followed this method - of setting a learning objective, planning how to meet it and then going step-by-step. We would demonstrate the method once a week, and the family would ensure that it was practised every day. Sometimes, we found that Bishu's sister-in-law had taught him a new word, or his father had taught him to recognise a new currency note.

Today, Bishu has graduated from our 'school'. He is able to write the words to express most of what he wants to say, and can add and subtract with ease. He now earns a full wage and the landlords no longer try to cheat him of his money.

Individual programmes may vary from a long-term learning agenda for the child, to referral for surgery in cases where this is appropriate. In some cases, we help in procuring orthotic and prosthetic aids and appliances and in learning how to use them. We also refer children with specific medical problems like epilepsy or tuberculosis to specialists or other institutions. In the case of children with epilepsy, where it is necessary for the child to have medication on a permanent basis, we sometimes help parents to bear the cost. In all cases, the emphasis is on helping the child to become a confident and self-reliant person. In case of children with multiple disabilities or who are mentally or visually handicapped, a primary concern is usually to develop self-help skills and help them to become independent in activities of daily living. In the case of children with hearing handicaps, whose major problem is communication, the usual focus may be on language skills using a combination of several methods of communication, and on enhancing the child's skills in understanding numbers. Wherever possible, we encourage children to attend normal schools, acquire basic literacy skills, help in household chores and become a wage-earner in agriculture, a family enterprise or as a local trade.

2. Services for adults and for children outside the field area

Our team conducts a weekly clinic for children with disabilities, in partnership with CINI-Child In Need Institute. Our clinic is a part of CINI's Thursday clinic for children under five. This weekly clinic provides immunisation, growth monitoring and health

services to any child below the age of 5. The clinic also serves as a referral point for children seen by health workers in the field. A corner of the clinic - a large shed - is ours, where 2 or 3 of our team are on duty. An average of 500-600 children attend, and children with disabilities are referred to us. We diagnose and assess the child, and advise parents about possible actions, where the child can be taken for an expert opinion or treatment, and what can be done for the child by them at home. Since the majority of these children come from areas sometimes several hours journey away from the villages where we work, we can follow them up only if they attend a subsequent clinic, or contact us at our office. As a matter of fact, some of these parents visit our office at regular intervals to report on the child's progress and get advise on what more they can do. Here again, our emphasis is on building a partnership with the parents rather than on prescribing a regime for the child.

Similarly, many adults with disability in the villages where we work come to us. Most of these persons have locomotor disabilities, and we are able to help them get mobility aids or prostheses.

3. Support programmes

We have been networking with other organisations working with disability, as well as with a number of development NGO's who would like to include disability in their work. Our objective is mainly to share our experiences in implementing a community-based rehabilitation programme, and our understanding of disability as a part of overall development activities. Our support starts from facilitation in conceptualising and planning the programme, to capacity-building for workers, and continuing field-level follow-up and interaction. Our emphasis is on exploring possibilities and modalities for integrating the rehabilitation of persons with disabilities into other socio-economic development activities. We had worked with Visakhapatnam Slum Improvement Project (VSIP) to help develop capacity of their workers to work with children with disability in the slums of Visakhapatnam. We are at present working

with Bhagavatula Charitable Trust (a NGO involved in rural development work in the coastal areas of Andhra Pradesh) as partners to build their capacity to work with people with disabilities and integrate them with their general rural development activities.

In our interactions with other organisations, we try to initiate and sustain processes which will help the person with disability and the family and community, to understand and analyse their present reality, to work out a strategy for change and to gain the self-confidence and the capacity to implement these strategies. When we started work, it was with the conviction that ordinary people, acting consciously and collectively, had the capacity to bring about change in the situations. We saw our role as facilitators in this process of people-centred and people-controlled development. This understanding is the basis for our continuing involvement in the regional Training of Trainers (TOT) programme in West Bengal. An offshoot of the programme at the National level conducted by the Society for Participatory Research In Asia (PRIA), this is a capacity-building exercise for persons involved in educational interventions at the community level. Participants in this programme include field organisers, programme managers and community workers. The focus is on understanding the basic framework of people-centered development processes in the context of one's own work, and on building competence and skills in facilitating participatory learning/training processes. For the last three years, we have been actively involved in running this programme with two of our team being trainers, and our organisation providing infrastructural and back-up support. We are also coordinating an emerging network of participatory trainers in the State. Apart from capacity-building for ourselves and others, TOT has also become a forum where we can raise the issue of disability in relation to overall socio-economic development.

Similarly, we have also been conducting brief training modules for Anganwadi Workers and Mukhyasevikas of the ICDS scheme in West

Bengal at some of the ICDS training centres in and around Calcutta. Although the ICDS personnel are expected to only identify and refer children with disabilities to the health set-up, we found that many women were interested in knowing more about the causes and prevention of various kinds of disability, and what could be done by the parents themselves. Our involvement in ICDS training has not only helped us to become acquainted with many members of this network, but has also been an opportunity to discuss and build on our ideas about integrating a child with disability into the activities at the Anganwadi centre.

Apart from this, we have been formally involved in providing a 'third opinion' based on our experiences and understanding to some organisations who have been working or are planning to work with disability.

ENHANCING OUR CAPABILITIES

Although each member of our field team deals with all kinds of disability, we have each developed aptitudes and skills in different areas. This is a function of our experience. For instance, one of us, who is in charge of our work in a particular cluster of villages where, by coincidence, there are a large number of cerebral palsied children, has developed higher level of skill in handling this condition than the rest of us. Another member of the team joined us with an interest in early childhood education, and focussed her efforts on developing skills in this area. We decided to sponsor her for a degree in the education of children with hearing handicaps. Another one of us is a qualified physiotherapist with years of experience in handling children with locomotor disabilities. Although the special skills of these persons are called on in the case of particular children, they have not become specialists in the sense that they do not deal exclusively with one particular disability. However, we feel that the team will be strengthened if we each focus

on deepening our knowledge and skills in one particular area, so that we can each be a resource person for the rest of the team. We are moving in this direction by allocating time and resources for individual capacity-building through formal courses, visits to other organisations and occasional in-house 'seminars'. However, we try to ensure that increase of competence in one area helps to enhance our understanding of other disabilities also, rather than making us exclusive specialists.

Our role as facilitators of learning for the child, family and community, as well as for workers in the field, has made it necessary for us to build skills as trainers. Our team is actively involved in the network of participatory trainers in the region and in evolving and practicing a method of training which is congruent with a people-centred and controlled development philosophy.

CO-ORDINATION & PLANNING

Our major co-ordinating mechanism is the monthly group meeting, at which each of us reports on our activities and shares what has happened over the past month. This meeting also discusses plans for the next month and responsibilities are assigned to be followed up by individuals. Any relevant issues or problems are also shared and discussed.

Looking back, our group meetings seem to us to be the major forum for our own development as individuals and as a group. Sharing our experiences in the field is the first step of a learning cycle - the data of individual experiences is collectively analysed, and concepts and principles derived from the analysis. We have found out for ourselves that technical expertise is not enough to deal with the problems of persons with disability, and have responded to the challenge by developing a more holistic and integrated perspective.

Apart from this, we also have weekly or fortnightly case sessions where the field team discusses three or four children in detail. The

child's condition and progress are reviewed and the whole team works together to plan learning programmes and suggest a course of action for the future. It is at these sessions that we also act as technical resource persons for each other, particularly in the context of children who need special attention.

The small size of our team has so far made it easy for us to co-ordinate and integrate our work. Our office has 3 small rooms and we are continually exchanging experiences and using each other as sounding boards. Sometimes, the weekly meeting is a continuation of a discussion that has been going on all week. Although there is division of responsibilities, with five persons having the field as their primary responsibility, one being with the support programme and one person being in charge of all administrative procedures, office management and accounts, there is a considerable overlap in all these areas.

Recording systems

Ever since we started working, we have been experimenting with various systems for recording our work. We maintain case files, one for each child, colour-coded according to nature of disability, organised separately for each village. Initially, we used to maintain a detailed documentation for each child. After some basic information about the child and family, the file would be updated after each visit to the child's home, with detailed accounts of what had been done, what had been discussed with the parents and what the child, the parents and family, and the worker felt about the situation. These early entries in the case files make fascinating reading, and record the complex process of building a relationship with families.

However, as the number of children we were working with increased, it became difficult to maintain these case files in the earlier detail and with the same regularity. Each member of the field team was visiting an average of five families a day, and returning to our office

late in the afternoon. Very often, writing up the case files would be put off to Thursday afternoon - we do not go to the field on Thursdays, since we have our clinic on that day. By the time Thursday came round, there would be 20 - 25 case files to be updated, and many details of individual conversations and interactions would have lost their clarity. Entries became brief and businesslike, recording only the bare outline of what took place. Often, vital information remained unrecorded.

Another problem arose when we needed to abstract data from our files. It was difficult to focus on individual details since they had to be located and extracted from the extensive process detail. For example, to find out how many of our children were going to school, each file would have to be read almost in its entirety since the information was not available at the same specific location in each file.

We have attempted to evolve a compromise between the two extremes of a rigid format where process is not recorded, and an unstructured process documentation where quantitative data is missed out or cannot be accessed easily. We now have our case files organised in two separate sections.

1. A set of three cards with information on the child's family and socio-economic situation, the child's condition and history and the child's progress after we have started working with the family. These three cards (the family card, history card and progress card) are designed to allow us to pinpoint each item of information by its location in a separate box on the card. For example, information about the family's productive assets is in the lower right hand corner of the family card.
2. Information on the process of our interaction with the child and family, on plain sheets which are added to the file.

The progress card is filled up after each visit to the family, and has information about the learning target for a particular period, as well as records of progress towards it. This data is recorded briefly, and the format ensures that nothing vital is left out. In addition, any significant new information about the family, as well as details of the process which seem important and worth sharing, are put down on the plain sheets. Some time is saved, with no significant details going unrecorded, since the formats on the cards have to be filled. Most of our field team now carry the files of the children they are visiting on that particular trip, and update the files at their homes. There is less of writing, and we are perhaps missing some of the richness of the process captured in the earlier documentations. This is a problem we have not yet been able to come to grips with.

However, our recording system is still far from perfect. In spite of reducing the amount of writing involved, it seems to become a burden at times and details are missed.

Assessment forms

When we started working, we planned to use standard existing formats to record the status of each child. When we used these systems, however, we found that many were too complicated to be practical, or did not relate to the kind of situation we were faced with in the field. As we continued with our work, we began to feel the need to develop a simple, quick set of formats for the assessment of children with various kinds of disability, as well as for recording their progress. Over the last year, we have been able to develop the framework of such a system through a process of trial and error. We use a simple grading system which enables us to set a target for the achievements of a particular skill, and follow the child's progress in achieving it. This system is still being tested.

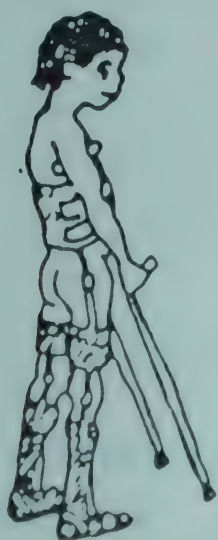
Chapter - IV

LEARNING AND INSIGHTS

Many of our earlier ideas, and aspects of our understanding of disability have been modified or deepened as a consequence of our experiences over the years. These insights are a part of the collective learning process in which we, and the children and families with whom we work, are involved. We would like to share some of these experiences, which seem to us to represent turning points.

1. Learning about appropriate interventions

When we started work, it was with the determination that all our interventions would satisfy certain basic criteria - they would be accessible, affordable, acceptable and appropriate. We felt that our major strength was our experience and expertise as professionals in the area of childhood disability. In many cases, particularly children with locomotor disabilities, we felt that a technical solution - aids, prostheses or surgery, fulfilled all our criteria. We presented this option to child and family as being the ideal solution to the child's problems of mobility. Increasingly, we are finding out that such interventions, which are all basically aimed at getting the child to move about 'normally', do not necessarily help to make life easier or movement more efficient. Gobindo's case is a typical example of such a changed situation.



Gobindo was 10 years old when we met him in 1989. He had had an attack of polio at the age of one year, and walked bent forward with a hand-to-knee gait. Gobindo is one of several children in the large family, which has his grandparents, parents, uncles and aunts and their children living together. The family owns a food shop, as well as some agricultural land, and is fairly well off. When we spoke to his parents, we found that they felt that their son would

be able to walk normally with the proper treatment. We referred Gobindo to an institution providing surgery, aids and therapy for orthopaedically disabled children, where he was fitted with a caliper (a knee-ankle-foot orthosis or KAFO). For our first few visits after this, we found Gobindo wearing the caliper, although he had difficulty in getting used to it. Soon, however, his mother complained that he would wear it only when he went to school, and not at home or when he went out to play. We spoke to Gobindo, who insisted that he felt more comfortable and could move faster with his hand-to-knee method. Since his family was very keen that he learns to walk 'properly' we continued to persuade Gobindo to practice more, though he did not seem enthusiastic. Last year, we found that the calipers had been shelved completely - Gobindo's excuse being that the bolt holding the ankle joint together had fallen off and got lost. We arranged for it to be replaced, but Gobindo now refuses to have anything to do with it, in spite of scoldings from his mother and aunt. He goes to school and moves around quite well in the way he has become used to doing. We have now decided not to persuade him into trying the calipers again. We have realised that the importance to others of Gobindo's gait being 'normal' is less relevant than his own feeling about what is best for him. The standard solution to the problem, which had the advantage of being time-tested and proven in many other cases, proved to be irrelevant and inappropriate in Gobindo's case.



Our experience with other children with various locomotor problems also strengthens our learning from our experience with Gobindo. A number of children who have undergone surgery or have been given aids are still not managing very well, while several others, who have not been referred, are getting on well with some help from us and their families. Similarly, many children to whom we gave wheelchairs prefer not to use them. The chairs are difficult to push over bumpy unmetalled village roads, specially when they become waterlogged in the monsoons. Many other conventional aids have been discarded by the children to whom they were given. We have now decided to give the child and family information about cases like Gobindo's, while discussing with them the available options.

2. Learning to work in partnership with families



Ever since we started working, we have been struggling to first define the kind of relationship we wanted to have with the families with whom we were working, and then to build up that relationship. We saw ourselves as persons with some technical skills and experience in the area of childhood disability, which we could place at the disposal of the community. We had, through our previous experience of working in community-based rehabilitation projects, developed a deep faith in the capacity of ordinary people to understand and analyse their own reality, and take informed decisions about possible interventions to tackle the situation. It was as facilitators to this process of choosing and implementing interventions for children with disability, that we introduced ourselves to the community.

However, we soon found that this was not quite the way in which we were perceived by the families of children with disability. Perhaps as a result of long familiarity with various service-based and 'charitable' programmes implemented in the area, both by the government and by other NGO's, we were also labelled as being in the business of distributing benefits and free services. Our assertions that we had nothing to give were interpreted as signals that only the lucky few - the well-connected or those with a special claim to notice - would be benefitted. Our first few contacts with a new family or community were therefore made in an atmosphere of suspicion. Even when people finally accepted that we would only help them to do what they themselves felt was best for the child, we were seen as the 'experts', who knew what to do, but for some reason were not giving any advice, prescriptions or instructions. It was very difficult for us to resist the sense of power that this perception

of our role endowed us with, and we had to keep reminding each other that we could perhaps never reach a depth of understanding of the situation, which matched theirs. As our relationship with many of these families grew and deepened, we learnt to accept each other and see each other in a more realistic way. Parents realised that we were often ignorant of many aspects of their lives which were crucial to their reactions to the problems of their child, so that many of the solutions which seemed workable to us could be instantly discarded by them. We, on the other hand, began to see that just talking about having faith in the ability of people to control their own lives, was not enough to give poor and marginalised people the confidence to think and act for themselves. Our individual personalities add a further layer of complexity to the situation - it is easier to talk of sharing power, than to actually relinquish a position of dominance and 'professional' control. We discovered that the process of building a relationship where we were equal partners was not a steadily progressive one - it often slipped back to an earlier stage, or something would happen which made a qualitative change for the better. We found that none of the 'standard' techniques for 'rapport-building' was universally fail-safe. Each individual, each family, is unique and what works for one may antagonise another.

Our experience with two of the children and their families have helped us to learn more about working in partnership with families. With Sabita and her family, we were successful in accepting each other as partners; with Babulal's family, we are still not sure where we stand or which way our relationship will go.

Babulal is a 6 year old mentally retarded boy. He is the youngest child of his parents, who have two other sons and a daughter. The family is a large one - Babulal's grandparents, their three sons (Babulal's father and uncle) and their wives and children, 13 persons in all, live together. Babulal's grandfather, father and uncle are quack doctors, treating their patients with allopathic medicines which they prescribe by rule of thumb.

They have a fairly busy practice. The family is quite well off, since the grandfather owns some agricultural land, some fishponds and a large house. Babulal's father also has a poultry farm, which, together with his medical practice, gives him an income of over Rs.2000/- a month.

When we first met Babulal in 1988, he could speak only a few words, that too indistinctly, was not toilet trained, was unable to feed himself and was extremely hyperactive with an attention span of less than a few seconds. His condition had been diagnosed by his father and uncle as "weakness of the hips and sensory nerves", and they were convinced he would become normal if left to himself. It was difficult for us to explain that the child was, and would remain, backward for his age, without calling their professional competence into question. Although not actively hostile, the family generally ignored us on our visits and went about their normal routine, leaving us alone with the child. We found it impossible to get anyone but the child's mother to sit and discuss the situation with us. Of course, Babulal soon became our friend and seemed to look forward to our visits.

Together with Babulal's mother, we had decided to involve him in activities designed to make him independent in self-care. We planned to teach him to bathe himself, eat by himself and to toilet-train him. At the end of the first year, we found we had made very little progress. We had asked Babulal's parents and grandfather to take him to the same spot every morning and each time he appeared to want to relieve himself, but this was not done with any regularity or consistency. On our weekly visits, we tried to make Babulal occupy himself with various toys and activities, but he could never concentrate for more than a second or two, since we sat in the front yard of the house and he was continually being distracted by the other children and the activities going on around him. However, we felt that we were gaining the confidence of Babulal's mother, who was slowly beginning to accept that her son's disability was a permanent one. Finally, after we had been making weekly visits to the house for over two years, Babulal's mother suggested that we have our sessions with him in an upstairs room where we would not be disturbed. This was a great advantage. Babulal's attention span increased to 10 minutes, and he began to learn to dress and undress himself, dry himself after a bath and feed himself.



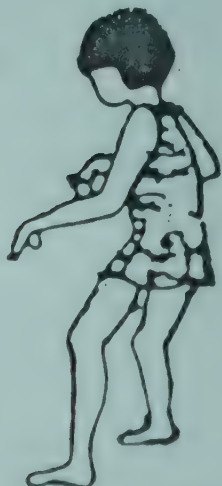
The situation with Babulal's father and other men of the family continued unchanged. About a year ago, the child began having frequent severe convulsions, and was referred

by us to a hospital, where he was prescribed a regime of anticonvulsant drugs. We explained to his mother that it was important to keep to the correct dose and to take the child back to the doctor at regular intervals. After about a month, we found Babulal's father had reduced the dosage of the drug since he felt the child was 'cured'. It was only when the convulsions returned that we were able to convince Babulal's mother to take him to the doctor again, get a fresh prescription and, this time, stick to the dose. At present, the convulsions are under control.

Babulal's mother continues to be the only person in the family with whom we have any kind of relationship. His father, who perhaps regards us as professional rivals, continues to ignore us although he is not actively unfriendly. Babulal's mother tells us that no one in the family has any time for the child. She herself is kept constantly busy with all the tasks of a large household, and can give very little time to the child. Progress is inevitably slow - sometimes nearly invisible.

Sabita is a 15 year old girl with cerebral palsy. The family - Sabita, her two brothers and parents - is very poor. Sabita's father does piece-work for a biri-maker. He brings home the tendu leaves and tobacco, and he and his wife roll biris on the veranda of their house. The eldest son, now 17, left school after studying upto Class V, and is now working as an apprentice in a motor workshop. The total earnings of the family are about Rs.600/- per month. Sabita's parents are both illiterate, and Sabita and her younger brother, who is now 6 years old, do not go to school.

When we first met her, Sabita's major problems seemed to be her inability to hold her head up straight, and the moderate spasticity in her arms and hands. She could walk, although she often lost her balance, and was more or less able to go to the toilet (although she could not clean herself), bathe and feed herself independently. She seemed to be a bright and intelligent child, with a lot of interest in learning. Sabita's mother was the person we interacted with, since she was always at home when we visited. We learnt that when Sabita's mother first realised that her daughter was not quite normal (when the child

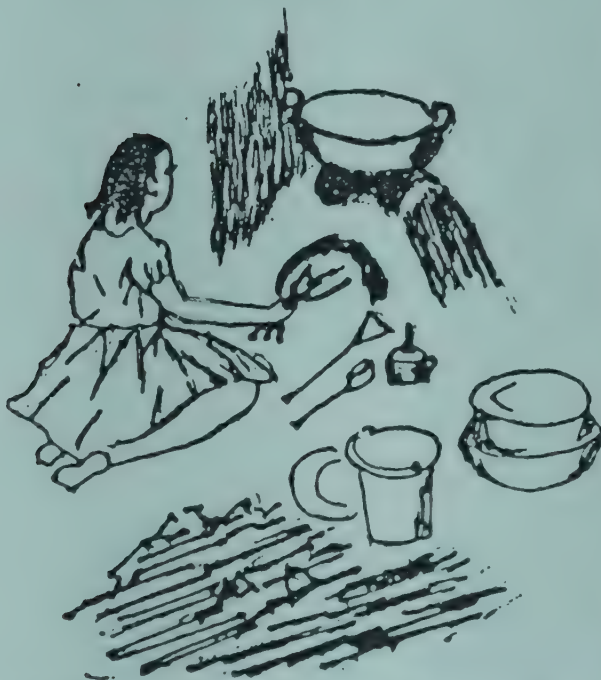


was unable to walk at the age of two), she took her daughter to CINI, from where she was referred to the Spastics Society of Eastern India. Since Sabita did not start walking after two or three sessions of physiotherapy, her mother took her to a neurologist where she was prescribed a vitamin tonic. She continued with the tonic for several months, but did not get the results she expected - the child did not begin to walk.

Disgusted and disappointed by her experience, Sabita's mother refused to even listen to us when we tried to discuss her daughter's problem. She was very clear - if we had anything to give her daughter, or the family, she was prepared to talk to us. If not, we could leave. On his third or fourth visit, she asked our colleague to stop bothering them - she was not interested in our work and did not want to have anything to do with us. That seemed to be the end. Sabita's file was closed.

In October 1991, another colleague, on a visit to a family with a deaf child who was a member of our programme and who lived very close to Sabita's house, found her severely ill with a respiratory infection. Without saying anything to anyone, he collected a course of antibiotics and some cough syrup for her from the CINI clinic and handed it over to Sabita's mother the next day. He also arranged for the child to be seen by a doctor from CINI. Sabita soon recovered.

This incident changed Sabita's mother's opinion of us and our work. Our colleague was invited to the house and had several discussions with the family. Everyone was involved in designing a programme for Sabita - helping her to keep her balance when walking, and using her hands and arms more effectively. In just a few months, Sabita, who used to spend the day sitting beside her father as he worked, is able to walk around the



neighbourhood visiting her friends. She learnt to hold a pencil and soon became an expert at colouring pictures. She can now write her name and also numbers upto ten. She is eager to help with the household chores - washing the dishes, sweeping and mopping the floors, cutting the vegetables. Initially her mother was a little apprehensive about letting her work alone. Today, Sabita can cook without any help from her mother. Every time we meet Sabita, she seems to have grown and learnt a little more, and we are encouraged and strengthened by the enthusiasm, support and friendship of the family. We feel

that Sabita will be able to cope easily with a normal school, and we are now planning to talk to the headmaster of the local primary school to see about getting her admitted.

3. Learning about the limitations of home-based care

The majority of the severely disabled children we work with are, slowly and unsteadily, progressing towards a stage where they will be independent to the extent of being able to at least

eat and perform their toilet activities on their own. For many of the others whose hearing is impaired, there seems to be an excellent chance of becoming economically self-reliant as well. The parents and families of these children are working out long-term strategies, which include the child with disability on equal terms with other members of the family. Although it has not been easy, a stage has been reached where the child is seen as a person who is capable of becoming something more than just a burden.

However, in some of the other families we are working with, there seem to be no answers. Chandrasekhar and Rupali are examples of such a situation.



Chandrasekhar and Rupali, brother and sister, are 16 and 14 years old. Both are severely affected with cerebral palsy and are mentally retarded. The family is a large one, with Chandrasekhar's parents, their eldest son who works as an agricultural labourer and is about 22 years old, another son who is about 17 years old and goes to school, and Chandrasekhar and Rupali who are the youngest. The children's grandmother lives in a room in a corner of their yard, and owns the land on which their hut is built, as well as some agricultural land, fruit trees and a pond. She lives on the income from these, and

gives Chandrasekhar's family a sack of paddy a year. She is not on very good terms with her son and his family. Chandrasekhar's father is an electrician with the PWD in Calcutta, and brings home about Rs.2000/- a month. This, and the eldest son's wages, are the family's income.

In each case, the parents realised that Chandrasekhar and Rupali were abnormal in some way, when they could not lift up their heads even at the age of 7 months. Each time, they took the child to various hospitals, doctors, Ayurvedic doctors and quacks, and tried out various tonics that were prescribed. After some years of this, when the children were 4 and 2 years old, they realised that there was no improvement in their condition, and gave up hope.

When we first saw him in 1988, Chandrasekhar could sit on his own without any support, though his legs had contractures and he could not straighten them out completely. His neck control was weak, and he constantly swayed his head backward and forward. He could, however, get about from end to end of the veranda of their house with a sort of rolling motion of the whole body. He could not stand, and was unable to grasp things with his fingers. His hearing and vision were normal, but he could not speak at all. He was not toilet-trained. He cried when he was hungry, but had difficulty in chewing and swallowing. He could drink only in small sips and with great difficulty. He was small for his age, and his mental level was that of a 2 year old child. He could recognise his parents and smiled when he saw them, but did not respond to others.

Rupali, who was 9 years old when we met her, two years younger than Chandrasekhar, also had poor neck control, but was able to sit without support, with her legs folded behind her. She could move from end to end of the veranda of their home by dragging herself on her chest and stomach. She could not grasp things when they were put into her hands, but could stand if she supported herself with her palms. Her hearing and vision were unimpaired and she could chew and swallow fairly well. Her mental age was that of a 1 year old child. She did not seem to recognise her parents or brothers, and did not respond to strangers.

The children's days follow the same unvarying pattern. In the morning, after waking them up and cleaning them, their father feeds each of them some biscuits soaked in tea or some leftover rice, before he leaves for work. Spooning the food into their mouths and waiting for them to swallow, takes an hour. While the father bathes, eats and leaves for work, the children lie on a piece of sacking in the veranda. Since they soil themselves frequently, their mother usually keeps them naked. Later in the morning, after she has finished her cooking and chores, their mother bathes and feeds them - this meal again taking about an hour, with the children having to be cleaned at the end of it. In spite of being small for their age, Chandrasekhar and Rupali are too heavy for their mother to be able to carry them easily. During the afternoon, when she gets a little time to rest, the children's mother locks them into their room, where they lie on a piece of mat and sacking. The mother generally goes and has a nap on the steps of the small family temple at the end of the yard, so that she cannot hear the children if they cry as they often do when they soil themselves or hurt themselves. After an hour or two of rest, the mother comes back to the children, cleans and feeds them and goes about her work after putting them on the veranda. When the children's father comes back in the evening, he sometimes, but not often, helps with looking after them. We have been told by the children's mother that her husband is in the habit of taking drugs and drinking occasionally and at such times he loses his temper with the children and beats them if they cry or irritate him in some way. When we got to know her better, she told

us that after making the rounds of all doctors and realising that the children would not improve, her husband had decided to speak to a doctor and ask him to give the children some drug to kill them, but she pleaded with him and saved them. According to her, her husband had asked her what she would do when the children grew older and she would no longer be able to carry them around. She had told him then that she would keep them locked up in a separate room. She told us that she realised that he behaved as he did, more from despair than anything else. Looking after these two children for the last 17 years had worn them both out and left them with very little patience. As one of our colleagues put it, she seemed to be wishing that the children would die, and had absolutely no hope of their ever improving.

The last few years of trying to help Rupali and Chandrasekhar have been very difficult. We started with plans of toilet-training the children and teaching them to feed themselves, since cleaning and feeding them were the tasks which were most exhausting and time-consuming for their mother. We have made little or no progress with Chandrasekhar, although Rupali has learnt to stand and take a few steps with support. The severe spasticity in their limbs combined with their mental retardation seems to make it very unlikely that they will ever progress very much from the condition in which we first saw them. There is very little we can do on our visits, other than take charge of the children for a while and give their mother some respite. Rupali seems to recognise us now, and will sometimes smile when she sees us. The children no longer remain naked all the time, but still soil themselves frequently.

A year ago, Chandasekhar's mother asked us if we could help to get a wheelchair for the children, in which she could take them out sometimes as they were now too big to carry. We were able to get them a wheelchair free, but it is a large one. Even if the two children are put in together, the chair is too big for them and they have to be tied in with strips of cloth. The family, especially the children's oldest brother, wheels them out with him to the village shop for an occasional outing. During the rains, however, the chair is unusable as the roads are too muddy.

For most of the last year, Rupali's mother has been ill with abdominal and chest pains. She has been asked to go into hospital for an operation. She does not know how this can be managed, or who will look after the children if she is away from home.

For Chandrasekhar and Rupali's mother, and for other families in the same situation, the question of who will look after the children when their parents are no more, is one to which we have no answers. The tremendous physical and emotional strain

involved in caring for such children pushes the parents (the mother in particular, since she is the primary care-giver) to the edge of complete break-down. When extreme poverty is added to this, it sometimes becomes impossible to cope.

When we started working towards forming parents' groups, at our first parents meeting in February 1991, we had discussed the possibility of parents providing some respite for each other, by taking charge of the child for short periods by turns. Even if this arrangement becomes operative, it can only be a temporary solution. Institutional care seems to be the only alternative for these children, provided it is free or very nearly free. We do not know of any such institution which would be accessible to these parents.

4. Working to form Parent's Groups

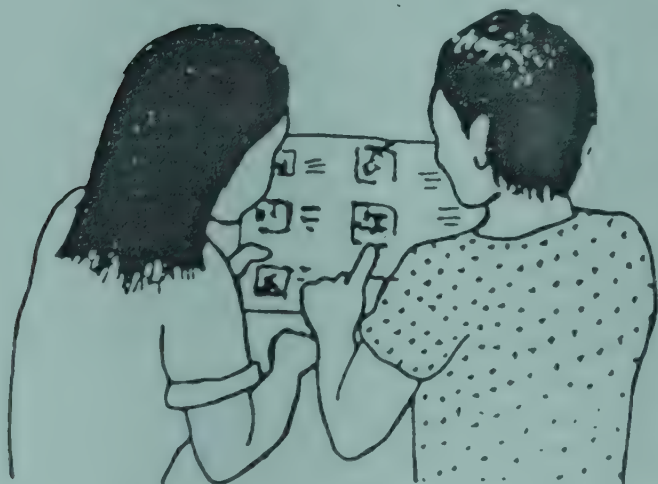


As a first step towards parents' groups, we organised a meeting at the SANCHAR office for the parents of the children with whom we were working intensively, in February 1991. This meeting was primarily an opportunity for parents to meet and share experiences. In many cases, the realisation that there were others in similar or worse situations, helped parents to look at their problems more

positively. Many suggestions were made by parents at this meeting. Our initial idea was that the whole group could get together and act collectively, but most parents felt that only small local groups of parents of children with same kind of disability would work, since the villages where we work are situated at a considerable distance from each other and it would involve considerable time and expense for parents to get together in one place. Our understanding of how parents' groups are formed and function has deepened as a result of our experience in conducting a learning programme for Ashish.

Ashish, who is now 11 years old, is the fourth of six children. He has been deaf from birth, and, as a consequence, is also unable to speak. His oldest brother, now nearly 20 years old, is also deaf from birth. The other children are all normal. Ashish's father is a worker in a small factory in Calcutta, and earns about Rs.650/- a month. The oldest son, who, although disabled and illiterate, is able to communicate and has his own interests and friends, also does odd jobs and brings home some money.

When we first met Ashish in 1988, he was a bright child whose major problem was his difficulty in communication. The family could understand most of his gestures, and had evolved a sign language of their own to 'talk' to him, but, like most children who are deaf, he was almost totally cut off from others. Occasionally, Ashish would grow angry and frustrated trying to explain something or ask something. He did not know the names of his parents and brother's and sisters, or of the village. He had no vocabulary to identify any of the things, people or animals he saw around him. He could not count. His parents felt that if he could learn to write, he would be able to communicate. They also wanted him to learn to count and be able to handle money, so that at some time in the future he could earn his own living. We decided to start Ashish on a programme to help him to learn the basic skills of functional literacy and numeracy, as well as helping him to communicate more effectively, and to become acquainted with his environment. Ashish's elder sister, who had eight years of schooling and who took many of the major decisions in the family, was appointed Ashish's main teacher. We started making weekly visits to the house and started teaching Ashish to write the names of the elements of his daily surroundings. We also started him on activities to help him form his concepts of numbers, colours, shapes and the calendar. His sister sat with us through our sessions and, for the rest of the week, continued with the lessons.



Ashish, an intelligent child, made very good progress and in two years, had a considerable vocabulary of nouns, was able to count and do simple additions and subtractions. He could go to the village shop and buy things, bringing back the correct change. At the beginning of 1990, we spoke to the Headmaster of the local school and he agreed to let Ashish come and sit in class, although he felt it would not be possible for the teachers to make special arrangements to teach him in the way to which he was accustomed. Meanwhile, his lessons at home were to continue.

However, after Ashish started going to school, we found on our weekly visits that his progress had slowed down considerably and he was forgetting many of the words he had learnt to write. We found that Ashish's sister was not giving him as much time as formerly, since she was busy with her own work about the house. The mother was also usually busy with housework, and Ashish's father was out at work all day. The problem was a serious one, since without constant reinforcement of what he had learnt earlier, Ashish would become confused and would soon regress to his earlier level.



It was at this point that we decided to try a different approach. Another of the deaf children in our programme, Rekha, lived in the same village, and was at more or less the same stage of learning. In fact, Ashish's mother and Rekha's mother were already friends and had even planned to take their children on outings together. We started having our weekly sessions with both children together, usually at Ashish's house. The mothers would sit and chat while the children learnt. We started involving Rekha's brother, who was a few years older than her and who was going to school. This plan did not succeed as well as it did with Ashish's sister, since Rekha's brother would keep running off to play in the middle of our sessions. However, the

children seemed to help each other's learning, and began to sit together in the evenings to practice writing and counting. Over the last few years, the group has grown to include Bishu, another deaf boy from the same village (much older than Ashish and Rekha) and Sabita, a little girl with cerebral palsy who is also learning to read and write.

Ashish is now fairly competent at handling money. He can lipread, and make himself understood to strangers through a combination of gestures and the written word. He now sometimes goes out on his own to work for some of the landowners in the neighbourhood at small jobs, and is able to calculate how much he is owed for the number of hours he has worked. He can also go to the local market and purchase the required items independently. His learning seems to have reached a plateau, however. He now can name all the objects, people and animals he sees around him every day, and is no longer interested in writing and re-writing the same words. The time has come for us to move to teaching him verbs, and expressing ideas through

the written word. The method we have been using to teach him nouns - using cards with the picture of the object, and its name written beside the picture, or pointing to the object or person and then writing down its name, is difficult to extend to verbs. Last year, after discussing with his parents (his sister got married and moved to her in-law). We started to plan ways of helping Ashish to move to higher level of communications - a stage where he will perhaps be able to read a book by himself or write a letter. During this time, Ashish's father lost his job. His parents were now more interested that Ashish should learn some trade (like carpentry or metal work) so that he can be economically independent. We have explored some possibilities of him being taken as an apprentice of a carpenter. At present, our efforts are focussed towards preparing Ashish to work as a carpenter.

We have found many of the parents, who had never met before in spite of living in the same village, have after getting acquainted at the February 1991 meeting, started visiting each other for informal chats about their children. In one case this contact has extended to organising a joint outing for the two families. In the beginning of this year, 16 children with their families had jointly organised a day's outing to the Zoo in the city. Each family voluntarily contributed some amount of money according to their capacity towards the expenses. For many of the families, this was the first time they were going out to the city. Following this in different clusters of villages, parents are joining hands to organise sports and outings for their children. It is significant that it is the mothers who are taking the initiative in making and maintaining such informal contacts, rather than the fathers, and who seem to draw strength from sharing each others experience and problems.

The problems discussed earlier, of the community initially identifying us as persons having a vested interest in distribution of some goods or services to selected 'beneficiaries', has had its effects on our attempts to float the idea of parents' organisations. In the case of other NGO's working in the area, as well as under some target-oriented government development programmes like IRDP (Integrated Rural Development Programme) and DWCRA (Development of Women and Children in Rural Areas),

efforts are made to form groups which can be then act as focal points for distribution of various benefits which cannot be easily channelled through individuals (eg. community biogas plants, loans for community dairies, financial assistance for economic development and so on). There was a general feeling that we were talking about forming groups, because we also had some such targets to meet and benefits to distribute. However, we have felt over the past years, that we are now sufficiently well known to the families and communities we work with. Our objectives are now understood and accepted by the community, and future efforts at bringing together parents to share each other's experience and provide mutual support will, we hope, be more successful.

5. Learning about poverty

Most of the families and children we work with are very poor, and have family incomes of less than Rs.1000/- per month. This poverty is a factor that colours every aspect of their lives.

It has been our experience that most parents feel a strong sense of guilt, as being in some way responsible for the disability of their child. This feeling is usually stronger in the case of the mother who is inclined to attribute it to factors like a fall or illness during pregnancy, complications during delivery or a lack of care during early childhood. This feeling is often reinforced by relatives and even health workers in the community. The social and cultural realities of life for most poor women in our villages include the fact that the almost reflex response - of the women herself, her husband, her family, her neighbours - in attributing to her the ultimate responsibility for most misfortunes in her family. Very often, such feelings may be justified - after all, a child may not have become brain-damaged if the delivery was carried out in a hospital, or may not have succumbed to polio if properly immunised. However, this

perception can be a powerful barrier to being able to make a realistic assessment of the child's problems, as well as affecting the child's self-image and the way in which the child and the parents relate to each other. A mother who feels responsible for her child's condition is likely to be over-protective, and to treat the child differently from her other children. In turn, the child relies entirely on her mother to look after her, becomes more and more demanding, develops a "royalty syndrome" and refuses to explore her own capacities and abilities. Although these feelings are perhaps common to the parents of any child who is disabled, they are more painful when combined with the thought that it would be possible to help the child if the 'treatment' could be afforded. Like anyone else, the families and parents we work with are prepared to try anything to help their child who is disabled. However, for these very poor families, access to the specialists and institutions in the city is limited because travelling there and the cost of the treatment is more than they can afford. The fact that many such 'specialists' continue to hold out hopes for a cure (for conditions such as cerebral palsy or mental retardation !) while prescribing expensive and useless vitamin tonics, makes matters worse. The family often sells off land and assets to buy these medicines, which, of course, make no difference to the child's condition. Finally, when the money runs out, the 'treatment' is stopped and the parents continue to think that it was only because of their poverty that the miracle eluded them. This is the state of mind in which we often find families when we first start working with them.

The ways in which families deal with the situation of a child with disability, is also affected by their poverty. In many cases, caring for the child becomes difficult since both the parents go out to work. The responsibility for looking after the daily needs of the child with disability then is taken over by another child, usually an elder sister, who then becomes

the key person for our work with the child. Even in families where the mother is at home all day, the burden of household chores leaves her very little time or energy to devote to the child with disability. In such cases, helping the child to become independent in the activities of daily living has immediate short-term benefits for the mother, apart from the long-term gains of increasing the child's confidence and self-image.

For a very poor family, the disabled child sometimes comes fairly low on the list of priorities. It has been painful but essential to understand that when the parents are not sure where the next meal is coming from, and have no security of any kind even for basic needs, it becomes impossible for them to have any confidence in their own capacity to change their

situation. The low self-esteem of persons living at this level, where survival from day to day is uncertain and therefore becomes the primary concern, is reflected in the way they see the child with disability. Parents seem to overlook the progress the child is making towards becoming a self-reliant human being. The child is seen simply as a burden, and parents are forced to take decisions which, to us, seem harsh and unfeeling, but which they see as the only option.



Sadhana's story is one we have often quoted as one of our successes. When we first met her in 1989, Sadhana was ten. She was born with brain damage, and was severely spastic as a result. Sadhana's family - her parents and three other children, all younger than Sadhana - is very poor. Both parents work as daily-paid labourers, at whatever work they can get. They live in a corner of the veranda of Sadhana's uncle's house, after their own hut was swept away in the rains.

Sadhana, when we first saw her, spent the entire day lying on a piece of sacking in this veranda. She could just manage to sit up by herself, but could not keep her balance. She was bathed and fed by her mother in the morning, and then left on her own. She would soil herself where she lay, and one or other of her parents would clean her when they found the time. Sadhana's father told us that he had taken her to an orphanage run by a missionary group when she was a baby (the family are Christians) but soon brought her back when he felt she was not being cared for properly.



We started initially with a programme to help Sadhana to sit up by herself. The process of designing and constructing a suitable chair attracted the interest of her father, who had initially pressurised us to arrange for sponsorship for his child, or some other financial help. Soon, the father became so involved that he took over from us and constructed an excellent seat by packing earth onto the side of the raised veranda, so that Sadhana could sit with her back supported and her legs dangling and separated. A bamboo table was made to fit across the front of this seat, so that Sadhana could feed herself off a plate. Within a year, Sadhana was pulling herself

around the courtyard on her stomach and elbows to a corner where she would relieve herself, and was helping her mother by picking and cleaning the rice and wheat for the family's meals, while sitting at the table. She had learnt to put on her pants herself, and could stand for some time with support. We planned to make a toilet for her - a pit over which she could squat while supporting herself by holding onto a bamboo railing. We felt excited at Sadhana's rapid progress, and had great hopes for her future. We had grown to be close friends of the family, and felt that Sadhana's parents, seeing all that she was learning to do herself, were slowly beginning to think of her as a something other than a burden. The child herself was bright and confident.

We were shocked when, in October 1991, on one of our weekly visits to Sadhana's home, we found that on the previous day, her parents had given her away to Mother Teresa, after signing an agreement to relinquish all their rights to the child. We could not understand how Sadhana's father, who had brought his daughter back from an orphanage because, as he told us, he could look after his own child better than anyone else,

could give her up once again. But as we spoke to Sadhana's mother about her difficult decision, we began to understand the terrible strains of their situation. Sadhana's father who had been working for some months in a steady job as a cook, had been dismissed by his employers and was now unemployed. The family was on the verge of starvation. Sadhana's father was becoming more and more frustrated. He would abuse and even beat Sadhana's mother in his rage, and she in her turn would sometimes slap Sadhana even though she realised the child was helpless. Neither of her parents had any free time to help Sadhana learn anything new - all her learning and progress was made during our weekly lessons. The veranda in which they lived was breaking down - the roof and much of the floor had been damaged in the rains. There was very little work for Sadhana's father and the family was reduced to eating only once a day. The parents sat up all night when it rained, holding pieces of sacking over the children. We had to admit that, in this situation, it was inevitable that a child like Sadhana would be a burden. As her father put it, "At least at the Home, she will eat her fill every day".

However, there are also cases of families as poor as Sadhana's, where the story is very different, Bhaskar is an example.

We first saw Bhaskar about 3 years ago, when he was $2\frac{1}{2}$ years old. He is the only child in a large joint family - his parents, grandmother, great-grandmother and grand-uncle all live together. His father has had about 4 years of schooling. Everyone else in the family is illiterate. Bhaskar's family does not own any land, other than the small patch on which their hut stands. Everyone except his mother and great-grandmother works as daily paid labour in the agricultural season. One or other of them is usually out of work, and the family income is supplemented with 'biri' making.



Bhaskar had cerebral palsy, with mild to moderate spasticity. His parents told us that he had not cried at birth. As an infant, he would whine feebly, almost all the time, and was weak and sickly. His parents took him on a round of local doctors, most of whom prescribed tonics and confidently predicted that he would get better as he grew. The family was very worried about the fact that Bhaskar, at $2\frac{1}{2}$, could not walk or speak, although he could sit by himself. He moved about by shuffling on his bottom in a rather uncoordinated way. His parents were not able to understand why this had happened to their child.

We talked about Bhaskar's condition and what was wrong with him. In view of the fact that he was only moderately affected, we felt there was a good chance of his learning to walk and talk, which his family said was their major concern.

We helped Bhaskar's father to design and build a simple bamboo walker for him, to help him to learn to stand and walk. In less than 7 months, Bhaskar had progressed from the walker to taking a few steps on his own, in a sort of running shuffle.

Bhaskar's parents, as well as the old people, were delighted with his progress, and eager to learn how they could help him more. We explained that all Bhaskar needed was encouragement to learn. Bhaskar's mother usually carried him on her hip if she took him out of the house. Now, she began to hold his hand and let him walk alongside her when she went to the village tank for her bath, or to the field with his father's mid-day meal. His father, too, took Bhaskar on walks to the village tea-shop in the evening, or on visits to the neighbours.

At the same time, Bhaskar was learning to talk. We had found that because Bhaskar did not talk, his mother and the others also did not talk to him much. We explained how children usually learned to talk, and how important it was to let him hear and imitate speech. Once everyone started talking to him, it did not take Bhaskar long to catch up with other children of his age.

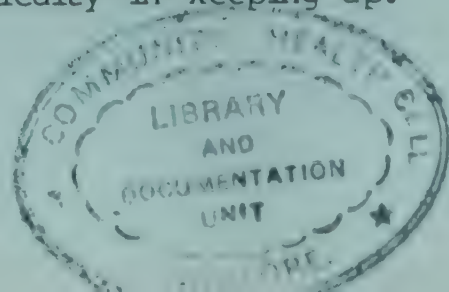
The young daughter of a neighbour (a distant relative) was another of Bhaskar's "teachers". We planned together how she could help Bhaskar to learn to read and write, and evening lessons were started, with the whole family enthusiastically applauding every new letter learnt.

Although Bhaskar was able to use his hands, he did not have much control of his fingers for finer movements like picking up small objects or holding a pencil. Like all children, Bhaskar loved to "help" his parents at their work. We suggested to his father that Bhaskar be allowed to trim the leaves for making 'biris' with a pair of scissors. Even though every leaf which was not precisely cut represented a financial loss, and Bhaskar would make a lot of mistakes in the beginning, his father encouraged him to keep trying until he managed.

Today, Bhaskar is a bright and confident child who, apart from his slightly unbalanced gait, is like other children of his age. His speech, though slurred, is intelligible. He is ahead of the other village children, in being able to write all the vowels in the Bengali alphabet, and count and write up to 5. He will soon be going to the village school, and we do not anticipate that he will have difficulty in keeping up.

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We look at all the factors which make Bhaskar's case different from Sadhana's - the fact that he is an only child (his parents have decided not to have another child, in view of Bhaskar's disability and the need to care for him), and a boy, the presence of his grandmother, the fact that his mother does not go out to work and can give him a lot of time. It is difficult to draw any conclusions about the individual importance of each of these, but the experience has taught us not to make easy generalisations about poverty and its effects on the lives of children with disability.

6. Learning about economic rehabilitation

When we started working with them, most of our children were in the 5 - 10 year age-group. Our priorities then were identical with those of the family - to help the child to become independent in self-care to the extent possible, as well as to grow into a member of the family unit on equal terms with others. From the beginning we have tried to emphasise and facilitate the child's involvement in the family's day-to-day life, by helping with simple chores. Depending on their physical capacities, the children help with cooking, dishwashing, cleaning or looking after poultry and livestock. However, as they grow older, the situation changes. In most of the families we work with, the level of poverty demands that a child become a wage-earner at the earliest possible age. In these villages, children only ten years old are agricultural workers, or contribute to the family income by doing piece-work, collecting firewood or cowdung or helping as an unpaid assistant in the family trade. The age at which the child is expected to become a worker either in the house, or outside is higher in the case of children with disability, but we have realised that the change in the perception of families and communities, from the child being just "another mouth to feed" to "another pair of hands to work" is an important step in our work.

We started with the belief that the best working environment for the child with disability would be the family. Accordingly, we started talking to parents about teaching the child the family trade. In the areas where we work, this is most often birimaking or needlework and tailoring. In both cases, the raw materials are distributed to various families by middlemen, who also collect the finished product and make payments, usually at a piece rate. With children who had mobility problems or hearing handicaps, we found that there were few problems in learning the necessary skills in the same way as other children in the family. However, with many others who were mentally retarded or had problems of coordination, we found that parents were rather reluctant to allow them to practice. There were various reasons for this - often, the time required for the child to master the skill to the level of turning out an acceptable product was too long to seem radical to the parents. Then again, we would go through the process of breaking up each activity into its component elements and helping the child to master each element at our weekly visits. However, it was necessary for the parents to help the child to practice for the rest of the week. Very often, parents engaged in a 10-hour working day found it difficult to spare the time for this - all the more so because it meant a loss of income. The person who looked after the child - a grandparent or younger sibling - were usually not skilled workers themselves, and therefore did not make good teachers. Then again, practicing the skill meant, inevitably, that some material would be wasted, again resulting in a loss of income for the day. All this, added to the fact that the finished product turned out by the children would be sub-standard for a considerable period, made the parents feel that it was not worth the trouble.

The alternative, it seemed obvious, was to help these children learn trades which would be suitable to their individual capacities. We had the experience of other groups in similar situations. The usual activities - making paper bags, agarbattis

or similar articles - were discussed with families. many parents were doubtful about being able to market these products without help from middlemen. We discussed the possibility of ourselves filling this role. However, we decided against this since it had been our experience that activities taken up with marketing support from organisations like ours never became self-reliant enterprises, since the family and child would continue to depend on us for its success.

There was also the problem of families dependent on agricultural work for survival, and who did not own any other productive assets. We discussed the possibility with some of these families, of trying to get government loans to help the child start some small enterprise, like a poultry farm or tea shop. Parents were enthusiastic about getting loans, but dubious about their ability to pay it back. Also, few children would be able to manage such enterprises on their own. The possibility seemed high that the operation would be taken over by the parents or the older siblings, leaving the child worse off than before. Many of our experiences in our earlier work seemed to follow this scenario.

As more and more of the children we are working with cross the 14-year old mark into young adulthood, we are learning that there are no easy or ready-made solutions to the problems of helping them become economically independent. All possible avenues have to be explored, while trying to balance the child's capabilities, the family's expectations and needs and the child's desires and dreams for a future. Our experience with Kalam seems to embody all these elements.

When we met him in 1989, Kalam was 15 years old. His major problem was deafness and a consequent inability to speak, although he was also mildly spastic, with weakness and difficulty in using his right arm and leg. However, this was not severe enough to hamper him in his daily life and he was able to look after himself and get around quite freely, like any other boy of his age. He was, however, a rather sickly child, and subject to frequent chest infections.

Kalam's family is very poor. His father transports goods in a rickshaw trolley, an occupation which brings him about Rs.20/- a day. Of this, more than half goes in drinking, and Kalam's mother runs a household on the remainder. Kalam is an only child, although his cousin, a little girl now six years old, is being brought up by his mother. The family lives in a little hut constructed of mats by the side of the road. It is illegal to occupy this land, but if they are ever evicted, they have nowhere else to go. A tiny pond of rainwater behind their hut is their source of water for bathing and washing clothes and utensils. Drinking water has to be brought from a considerable distance away.

Kalam's mother is an intelligent and articulate woman. In spite of their difficult circumstances, she keeps their home sparkling clean with the floor swept smooth, the walls papered with pictures cut from old newspapers and her few cooking vessels gleaming. She told us the first time that we met her, that she did not rely on her husband to do anything for Kalam, since he could barely look after himself. Her primary concern for her son was that he should learn a trade or be employed somewhere, so that he could earn his own living. She had tried to teach him to make paper bags, but Kalam had difficulty in using his right hand to paste the sides together.

We discussed the options. Since the family had no land of their own, looking for a job was the only possibility. Kalam - who was able to communicate quite efficiently with gestures - made it quite clear that he wanted to work and earn money of his own. He would sometimes go and join the gangs of men working in someone's fields or at digging a pond. He would try hard to work as fast and as efficiently as the rest of the men, many of whom would encourage him. At the end of the day, however, the landowner would often refuse to pay him, on the grounds that he had not been asked to work, but had forced himself into the team. Even when he was paid, it was only a fraction of what he should have earned. Kalam had taken to spending most of his time at the local video parlour, refusing to listen to his mother when she scolded him.

Kalam's mother had thought of asking the owner of the local cycle repair shop to employ him. She felt that he could work there even if he did not earn very much - after he learnt the trade, she would help him to start his own repair shop. The shop owner was initially cooperative, but after a day or two, he sent Kalam home. He told us that keeping the boy on would mean employing an extra person to supervise him, since Kalam was not able to learn fast as the other apprentices.

Kalam's mother now thought of opening a small tea stall on the roadside near their hut, where Kalam could serve tea and snacks. We thought this was a good idea. Although Kalam could count and add small sums, he could not recognise numbers and was completely illiterate. We started teaching him to recognise and read the names of objects around the house, as well as words like 'tea', 'cup' and

'biscuits' which he would need to communicate with his customers, as well as to recognise coins and notes, add and subtract and give the correct change. Kalam's progress was fairly rapid. Although it was easier for him to use his left hand, he insisted on learning to write with his right hand 'like other people'.

The tea stall was opened but did not last very long. As soon as a customer appeared, Kalam's mother would leave whatever she was doing and dash out to make the tea. But customers were few, most people preferring to go to familiar and better-equipped shops a little way down the road. Both Kalam and his mother now became depressed. Kalam took to coming home only at mealtimes and refused to continue with his reading and writing lessons.

Recently, and purely accidentally, we became acquainted with the owner of a chain of motor garages who became interested in us and our work. He told us that he had, for a long time, been thinking of employing some boys with disability, mainly to help with washing cars and doing odd jobs around the garage. Kalam has been introduced to him and has been taken on. He will be paid Rs.300/- a month, like the other boys doing the same job and, if he shows an aptitude for the work, will be promoted to assisting the mechanics at minor repairs. Kalam's mother was initially doubtful whether the work would suit him - the garage is a forty-minute bus ride away from their home, he is susceptible to chest colds and does not like getting wet, he will not be able to use both his hands, he will not be able to hear cars driving up behind him and so on. However, Kalam responded with excitement to the businesslike atmosphere at the garage, and the sight of boys only a little older than him going about their tasks with professional confidence. The garage owner assured us that if Kalam performed well, there was scope of similar jobs for more boys like him.

We visited Kalam's house a few days later to find out how he was getting on, and found that he had not been to work at the garage after his first day. His mother told us that he was afraid of catching cold or falling ill if he worked there. She told us that he was now saying that he wanted to study and learn to drive.

Looking back at our experience with Kalam, it seems to us that, in spite of our disappointment, we have learnt some valuable lessons. It now seems fairly obvious that the primary reason for Kalam's failure at everything he tried is his mother's attitude towards him - he is an only child, and she cannot bear the thought of him being put to any physical discomfort, or having to struggle to earn a living. We, in spite of all our efforts, have not been able to appreciate her point of view. Her aspirations for her son's future - a comfortable, easy, well-paid and risk-free occupation - seem to us

to be unrealistic and impractical. Our programme of functional literacy for Kalam, which was intended to help him to communicate, has been interpreted by him as 'studying' for its own sake, and has perhaps been responsible for giving him the idea that it will lead to a job of a different kind.

This lesson - that it is the attitude of the child and family that determine the employability, rather than our assessment of potentials and possibilities, has been reinforced for us by our interaction with Mujibur.

Mujibur, when we met him, was 16 years old. He was working in a tailoring shop in the small town near his village, and was a fairly skilled and well-paid worker. One day, as he was cycling to work, he was knocked down by a bus. He was seriously injured, and his right leg had to be amputated above the knee. Mujibur's father brought him to see us to find out what we could do to help him, and to enquire about the possibility of getting a wheelchair for his son.

Mujibur's father told us that although his son had recovered his health, and his former employer was eager for him to start work again as soon as possible, Mujibur was refusing to go out of the house, or meet or talk to any of his former friends. He was ashamed of having only one leg, and was going deeper into depression every day. We had a long talk with the father, and started visiting the family once a week to chat with Mujibur and try to cheer him up. Although initially reluctant, Mujibur finally agreed to be fitted with an artificial limb. The limb was a success and Mujibur was soon walking. We also arranged to get him a tri Wheeler free of cost, so that he could go to and fro from the shop.



However, in spite of everything, Mujibur refused to go back to his former working environment. Following prolonged discussions with him and his father, possibilities were explored to get a loan from the bank so that Mujibur could work from home. The attempts to get a loan from the bank did not materialise. Finally, Mujibur's father helped to borrow some money and built a small room in front of their house. One of Mujibur's uncles

presented him with an old sewing machine with which Mujibur started his business. Over time his business started growing. We helped him to buy another sewing machine by providing him a loan.

Mujibur has been running his own business for over a year now, and is quite successful. He is no longer the depressed boy we first met. He feels very confident of his skills and his new-found success. When we last met him, he asked us to organise a new artificial limb for him - the old one was growing too small. He is also considering the possibilities of employing a few other children with disabilities.

7. Learning about awareness generation

When we started working in this area, most people in the community were aware of the presence of children with disability in their villages. However, few among them had a very clear idea of the precise nature of the disability, its causes and how it could be prevented. In many cases, although awareness existed, it was not acted upon. For instance, in spite of several awareness campaigns over the last ten years, emphasising the importance of immunisation, and regardless of the fact that parents knew that a 'medicine' to prevent polio was available free of cost, many children below the age of ten have had the disease. Many parents have told us of cases where a child, after a dose of polio vaccine and a triple antigen injection, has become paralysed. Although this 'knowledge' is based on hearsay about the handful of cases where this has occurred, it determines how the parents will act, and is not countered by the songs, folk tales and street plays about the need for immunisation the child which are the usual methods of awareness generation used by NGO's in the area.

We have experience in our work of participating in various "awareness generation programmes". These took the form of information transfer, in packages which we felt would be most easily assimilated by our community - in the local language and using folk media. However, the strongly-held beliefs of the community - that disability was a punishment for the sins

of the parents, a curse or a curable disease - did not in our opinion, change significantly as a result of these campaigns.

Looking back at our previous experiences, as well as analysing other disability awareness programmes, we found that most of them focussed primarily on prevention of the condition. Emphasis was always on the negative aspects of each condition, with pictures being chosen for their potential to shock, disgust or arouse feelings of pity. The message to parents was - "If you do not take care, this terrible thing may happen to your child as well". The effect of these messages on parents, especially mothers, of children who were already disabled, was predictable - they served to enhance the feelings of guilt and helplessness which were usually already present, as well as to reinforce the perception of the community about the "horror and hopelessness" of disability. When we tried to present the positive aspects of the situation to these parents, it was as if we were trying to combat the contradictory signals sent out by the prevention campaigns - as if we were saying "Don't let this happen to your child, but if it happens anyway, don't let it make you feel bad !" There was very little in the awareness material that focussed on disability as an issue.

We now believe that a better understanding at the community level of various disability-related issues - economic, social, cultural, medical and psychological - is essential for the person with disability to be accepted on equal terms. Initially, we decided that our direct interactions with the community, primarily through the village-level women's groups and neighbours of families with children who were disabled would be used as our major tool of creating awareness in the community. However, as time went by, we realised that most of these women's groups were primarily concerned with the sharing out of material benefits available from schemes like child sponsorships. The large majority of women in the village, particularly those from poorer families, did not participate in the group meetings. As a result, very few critical issues were discussed.

A recent experience in one of our villages has strengthened our belief that changes in the attitude of the community towards those of its members who are disabled do not come about by mere acquisition of information, but rather through processes which allow others to directly experience the person with disability primarily as a unique human being with strengths and weaknesses like anyone else.

During discussions with a group of parents in one of the villages where we work, the idea of holding our weekly sessions with the children in a common place, rather than going separately to each child's home, was put forward. Since most of the children concerned are hearing-handicapped, and are going through a learning programme for functional literacy and numeracy, the parents felt that it would be a good opportunity to approach the local school. We went to meet the headmaster, who was friendly and cooperative. He readily agreed to let us have a room in the school when classes were not going on, after school hours or during the holidays.



The first time we had a 'class', in the schoolroom was an exciting experience for the children. As is usual in most villages, as soon as we started work, a crowd of children gathered to watch. Many were brothers and sisters of the children we were working with, but some were from other families. Some of the latter went and called their parents to see what was going on. Very soon, we had a considerable audience - people who strolled over from their homes to see the fun, idlers from the nearby tea shop who came to see what the crowd was doing, and, finally, the local paanchayat pradhan who happened to be passing by. To our surprise, everyone stayed for the entire session and watched the children with interest.

The crowd - many of them illiterate - watched these children whom almost everyone in the village thought little better than idiots, writing, reading and doing sums. At the end of the session, we were bombarded with questions - how long had we been working with these children? Why was it that they could not speak properly? Could they be cured? There was universal admiration and appreciation of the fact that the children were capable of this level of sustained effort.

As we were leaving, the panchayat pradhan - the head of the local power structure - came a little way with us to assure us of his help if we needed any further facilities from the school, an unsolicited "official" blessing !

This particular village was one we had been working in ever since we started, and we were well known to the community as people who went to the families where a child was disabled. However, any change in the children we were working with had so far been visible to only a limited circle. Although it may have been passed around by word of mouth, the impact of actually seeing what the children could do, and realising that they were in many ways more advanced at what they were learning than other children of the same age, made an impact that, we feel, will be a basis for change.

We have now decided, as far as possible, to make the children visible to the community in different ways - by encouraging them to come out of their homes, by creating opportunities for others in the community to know them better, and by ensuring that they get a chance to display their skills.

8. Learning about 'Therapy'



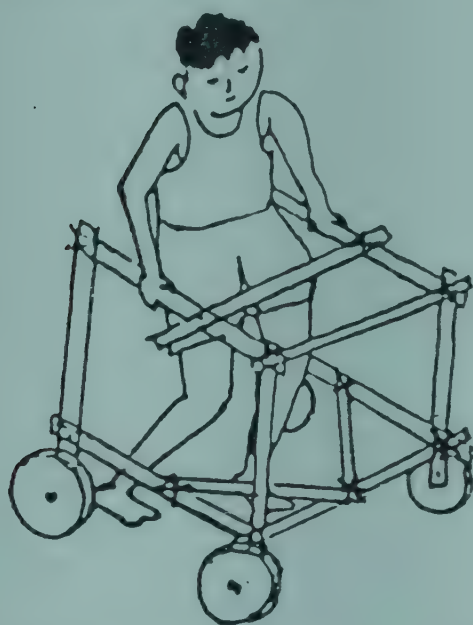
As rehabilitation workers, we have available to us an immense resource in the form of therapies designed to improve the condition of children with disabilities and help them to learn skills. These usually take the form of exercises - to help to relax spasms in cases of spasticity, to build up muscle strength,

prevent contractures and deformities, to help develop motor skills to help the child to learn to speak and so on. However, experience has shown that this collection of standardised therapies, where a particular intervention leads to a specific result, is not always useful in practice. Although these exercises are always simple and easy for the parents and families to supervise, they are often seen as a mechanical and unproductive activity, boring for the child as well as for the parents. Progress is never fast enough to be exciting. Parents continue to feel that the child is helpless and not capable of learning, and, as time goes on, they lose interest in the exercises.

The challenge for us was to develop ways in which we could help children to learn necessary skills through activities which were not alien, and which seemed purposeful even in the short run. We have also realised that, for the parents, feeling that a child with disability is also a person who is able to do a lot of things comes when the child does something that very obviously benefits or helps the family. For example, fine motor coordination and skills can be learnt through activities like cutting out paper dolls or stringing beads. In fact, this is standard practice in institutional set-ups. Initially, we tried to modify this and make it more meaningful by incorporating it into learning a self-help skill, like practicing putting buttons into buttonholes. However, we found that even when the child had learnt to fasten buttons, the parents did not recognise it as a significant advance. On the other hand, when the same child was able to pick and clean the rice for the family meal, or cut vegetables and sort greens, the parents were convinced that the child was contributing to the family. We now emphasise day-to-day activities and skills in our learning programmes - simple household tasks like washing the dishes and clothes, feeding and looking after the poultry or cattle, sweeping the floor or sorting and cutting vegetables. These are skills that parents are confident of being able to teach, which have the

added advantage of getting some work done and giving both child and family a sense of purpose, achievement and confidence. This whole area is still a challenge for us. There is always the need for us to delearn what we have learnt of conventional therapies, and devise activities which meet the technical criteria as well as being productive and enjoyable. There is also the risk that an innovation which has worked for one particular child becomes the standard pattern to be applied in all similar cases. The pressure has to be kept up, for us to think creatively rather than fall back on tried and tested stereotypes.

9. Learning about 'Aids'



From the very beginning, we have tried to help make 'appropriate' aids for the children who need them. Over the years, we have learnt to respect the skills available within the locality. Most of the aids are made with active involvement of the parents using whatever is available at home. The experiences with children like Sadhana where a seat was

made from mud using the floor itself was a tremendous learning for us. We have used it for many other children. Bhaskar's walker was made of bamboo. In almost all the instances, it was a challenge for us to use materials available within the



home and neighbourhood and once the family understood and recognised the need, they were the main architect. Using simple materials and ideas which are not completely alien or 'foreign' helps people develop understanding of the aid, it's need and enhances their confidence in their ability to contribute towards its design and fabrication, thus enriching the aid.

We also feel that a lot of work is needed to design and fabricate aids, appliances and educational materials using local resources which are appropriate for the rural people.

Chapter - V

DEFINING OUR APPROACH : A LOOK AT STRATEGIES

When we started working, our primary objectives, as stated in our first Annual Report, were :

- Initiating community-based rehabilitation services for children with disability in the area, helping them to become independent and self-reliant.
- Extending support to other organisations working or planning to work with the disabled.

Five years down the road, we feel it is appropriate to look critically at the strategies we have adopted to meet these objectives. When we started working, it was on the basis of a limited perspective and experience. Our initial idea was merely to provide some services at home level, while simultaneously linking with existing community groups to facilitate collective action on the issue of disability. As we gained experience, we have moved towards developing a more holistic perspective and a clearer idea of the meaning of empowerment for the individual with disability, the family and the community, and our role in facilitating this process.

As we understand it, analysing our strategies will enable us to progress towards our objectives, while ensuring that we have a range of options and the flexibility to adjust to the immediate demands of the situation.

Our various activities at present fall into distinct groups, representing different strategies :

1. Working with individuals with disability, towards individual empowerment and rehabilitation. This includes all our services to children with disability in and outside our field areas.
2. Working with families towards acceptance of the child with disability as a member on equal terms with others, and towards collective action to tackle issues of disability in general. This includes all activities for building a partnership with parents and facilitation of parents' groups.
3. Working at the community level to advocate and facilitate acceptance of children with disability on equal terms with others, as well as community action on issues of disability.
4. Sharing of experiences and mutual learning through interacting with and supporting other organisations.

In assessing the impact of these strategies, we need to first set our criteria for "success". In other words, how will we judge when a child we have been working with has been empowered to the extent of no longer requiring our continuous support ? We have been able to identify the following indicators :

1. When the child becomes confident of being a person who is capable of learning, growing and taking control over the situation.
2. When parents become confident that the child can learn, change and grow, and that they can provide the necessary environment and support for this growth.
3. When children become economically self-reliant and independent.

4. When the child is seen by the community as being perhaps different from any other child of a similar age, in some respects, but no less in ability, and no less a person.
5. When there is a deeper community understanding of disability issues, and community organisations take over the role of providing support to children with disability, using us as a resource.



Of the children we are presently involved with, those with locomotor disabilities (mostly post-polio paralysis) satisfy one or more of these criteria. Our support to these children is now limited to periodic follow-up visits to maintain contact and keep track of the child's progress. Many of these children now attend normal schools, while the others are wage-earners or share family chores.

Another group which may reasonably be considered to have achieved control over its life and situation is made up of children with hearing handicaps. When we started working with them, all these children were already independent in activities of daily living and did manage to communicate with their families, if not with outsiders. Our interventions were focussed on development of effective communication skills. In spite of a cultural predilection to associate the inability to hear and speak with a lack of intelligence, the majority of these children are now accepted and encouraged by the community. Many are wage-earners.

It is more difficult to assess the extent of rehabilitation in the case of children with cerebral palsy, multiple handicaps or mental retardation. At the lowest end of the scale are children with very



severely disabling multiple handicaps, for whom the possibilities of ever becoming self-reliant or independent, either in the activities of daily living or economically, are almost non-existent. For these children, it seems logical that our interventions should be directed to bringing about community involvement in assuming responsibility for their care.

At the other end of the scale and falling along a continuum, are a group of children who have become completely or partially independent in self-care, and for whom there are strong possibilities of economic independence as well. Although family attitudes towards these children have become more positive, in no case have the parents or family gained the confidence to take over our role. At the community level as well, these children are still seen as helpless and dependent.

As we understand CBR now, the effectiveness of any strategy must derive from its potential to bring about changes in - individuals, families and communities. Change processes initiated at any one level must be supported and reinforced by corresponding processes at the other two levels to become self-sustaining in the long run. Activities designed to create these linkages across levels, as well as strengthen them subsequently, therefore seem to us to be the most strategic interventions. It is in this context that we have attempted an analysis of our major interventions and the problems we have faced in implementing them.

From individual to collective processes

From the outset, our strategy in this area has been to work in partnership with the child and family. The process of learning enhances the self-image and self-esteem of the child, while simultaneously changing the perceptions of the family, and increasing their sense of control over the situation. We try to consciously strengthen this link by recognising, valuing and building on the knowledge and skills they already have rather than using only what

we know. For instance, in working with a child who is mentally handicapped and who does not communicate, we help the parents and family to understand the complex process by which a child learns to use language hearing sounds, imitating them forming them into words and attaching the correct meaning to the words and so on. All parents help their children in this process by talking to the baby, demonstrating the meaning of a word by linking it to an object, repeating words until they are correctly imitated and put together into sentences. The parents and family of the child who cannot communicate have also taken part in this process with their other children, and therefore have these skills. However, they are not aware that this 'normal' activity actually represents a valuable source of experience, and a skill which can be put to use. By helping them to become aware of this, we also help them to combat their feelings of powerlessness and helplessness in the face of their situation. We, as professionals, can build on and reinforce these skills more effectively and facilitate their use, thereby helping the child to learn to communicate better, whenever possible by speaking.

The extreme poverty and deprivation of most of the families we work with, is the major factor shaping the way in which they see themselves, as well as their child who is disabled. Feelings of helplessness and ignorance are reinforced by the daily experience of powerlessness - economic, social, cultural and political, in every aspect of their lives. When the economic and physical burden and social stigma of having a child who is handicapped are added onto these, it is very difficult to even see the possibility of change. The process of learning is a slow and difficult one for many of these children, so that acquiring even the simplest skill can take months and progress is slow and imperceptible. The mutually reinforcing nature of the two processes leads to a situation where the continued negative attitudes of the parents make it even more difficult for the child to learn, and the child's incapacity strengthens the parents' conviction that no change is possible. It is difficult to break this cycle and there are no guarantees that a positive attitude, once developed, will not regress again.

One way in which positive experiences can be reinforced is through interactions between parents and children from different families. Apart from being a source of strength and support these gatherings have the potential of leading to the formation of parents' groups which may later become the basis for collective action.

Our earlier strategy of visiting each family separately and building up partnerships on an individual basis also led to some practical problems.

1. With each worker having to interact with four to five children during the weekly visit to the village, the time available for each family becomes short. In addition, energy and enthusiasm are reduced with each session, so that, with the last family to be visited, the interactions is qualitatively poorer.
2. The child works and learns alone, and does not have the opportunity to feel enthused and stimulated by other children who are tackling similar situations.
3. The child and family develop a deep relationship with the person who is 'their' worker, which facilitates their learning. However, this relationship often has an element of dependence, so that if, for any reason, that particular worker is substituted by another person, the child finds it difficult to learn.

Our first attempts to develop a collective approach were a response to this situation. We had been working with a home-based approach in the first twenty villages in our field area. Two years ago when we initiated activities in 10 new villages, we changed our pattern of working. After identifying children with disability and contacting their families, we organised meetings at a central place where all the parents came with the children. We had a day-long session where we assessed the children and discussed strategies with the parents. It was finally agreed that, on one fixed day in the week, the child,



accompanied by a parent or the person who was the primary caregiver, would come to the common meeting place for the learning session. The session would be attended by as many of our field team as practical, with at least two of us always there. We have been working in this way for some time now, and find that the children in these villages are stimulated by being in a group. Also, those parents who come to the session spend the time talking with each other

and are gradually building a relationship. Many parents of children with severe disabilities who need constant attention, also appreciate the respite they get when the child is with us. With children working in groups at approximately the same stage of learning, we are able to give more time and attention to each group. However, we have found that the group approach has its own limitations.

1. Our relationship with families in villages where we have adopted a group approach is qualitatively poorer than in the earlier villages. Although we did initially make a visit to each home, our subsequent interactions have been with one member of the family, often a different person each time. We have met very few fathers, and are not part of the family's daily life and struggles, sharing each others troubles as we do with the families we visit in their homes.
2. When working with groups, we find ourselves getting more technical. Perhaps because our relationship with the family is more superficial, we tend to focus exclusively on the needs of the child to determine the learning agenda. This has reduced the extent to which we tailor individual programmes for each child. Instead, we tend to market approaches which we have

tried and found effective with other children. For instance, we are tempted to recommend a functional literacy & numeracy package for all the deaf children in the group, or a particular set of exercises for all the children with cerebral palsy.

3. Many parents in the villages where we work with a group, tend to think of our sessions as a kind of school to which they send the child, and of us as teachers. This is particularly so in the case of deaf children who are going through a functional literacy programme. These parents - and many of the older children - begin to think of learning to read and write as an end in itself, rather than as a tool for communication with the world which is how we see it.
4. In many cases, the child with disability is brought to the group by an older sibling, who goes off to play until it is time to take the child back home. It sometimes becomes difficult for us to find out what has been done during the week by the parents, and what progress the child is making.
5. Since, during most of the time we are in the group, we interact with each other rather than with the parents, we find ourselves getting more 'technical' than we used to be. Earlier, we would take care to avoid using terms which the parents and family could not understand, and which would increase our 'professional' aura. In speaking to each other, we are not always so careful.

We now plan to counter these problems by using a combination of the two approaches. A strong relationship with the family will be built up through working with the child at home in the early stages. It is only after the initial period of mutual adjustments, and when a solid basis for a partnership with the parents has been established, that we will move to working with groups. Even afterwards, we will continue to maintain this contact by visiting the parents at home at frequent intervals.

Having a clearer idea of the pros and cons of individual and collective approaches, we are now looking for ways to strengthen the collective process so that it leads to a greater degree of control by the persons concerned. Our experience with parents so far has been that the process of gaining enough confidence to plan and implement change



strategies independently of us, is a slow and painful one. In spite of our continuous efforts to reject the 'professional' label, there is an impression that we are more qualified to decide on what the child should learn and how. Although there are notable exceptions, the majority of parents have not gained the confidence to implement a learning programme entirely on their own, even when the skills being taught are simple everyday ones like eating, bathing or dressing. All parents teach these skills to their children, but in the case of a child who is disabled, the fact that the child is older, and learns so much slower seems to make the process alien and artificial.

On the other hand, we have found that, when they are confident of their skills, parents are more than capable of being excellent teachers. For instance, in the case of children who are learning the family trade - biri-making or tailoring - where a high degree of skill is required, we have found parents planning and implementing an entire learning programme, breaking up the necessary skills into smaller units, teaching each of them step-by-step and monitoring the child's progress. It is interesting that our own lack of skills in these particular areas seems to be a factor in increasing the parents' involvement and confidence.

We feel that some specific steps have to be taken to make the link between the child's learning process and the family's process of gaining control over their lives and situations stronger and more positive, as well as ensure that this enhanced control leads to a collective process of analysis and action.

A. Capacity-building for parents

A more structured and intensive effort to enhance parents' skills in planning and carrying out interventions with their children needs to be taken up. This could be through short sessions at the home of one of the children in a particular village, where parents of other children in that village with the same kind of disabilities could be invited to attend. We could present some information about the nature and causes of the disability, and share what is usually done to help the child. Subsequent sessions (in different homes) could provide opportunities for supervised practice of skills, as well as clarify certain points with regard to specific individual problems. Short meetings of parents with experts in one or other subject could also be arranged at our office. At present, we do get help and cooperation from various experts and specialists, but this is usually in the form of advice on individual problems, and the interaction is only with us. Meetings with groups of parents, all of whom have children with similar disabilities, would

provide the space and opportunity for parents to ask questions directly rather than through us and, in the process, build their confidence and cohesiveness as a group.

On the other hand, it needs to be kept in mind that the simple steps and techniques that may be shared in such learning sessions will by no means provide answers to all the problems that may arise. To acquire the confidence, information base and flexibility required in helping children with severe mental handicaps, developmental delays or multiple handicaps, requires an intensive, time-consuming and painful process of ongoing learning. Our role as facilitators of these ongoing processes may take us back to the individual level, since all parents may not have the same capacity, motivation or pace of learning, and also since these processes will be built around individual situations.

B. Facilitating parents' control of children's learning groups

In the villages where we have established a successful learning group, parents could be asked to volunteer to run the activities at each session. The various factors limiting the involvement of parents (particularly mothers) in activities outside the home, such as the pressures of housework and childcare as well as working for a wage, would have to be taken into account in soliciting this involvement. Unemployed fathers, mothers who have an older child, mother-in-law or sister-in-law to carry on with household chores for a short period on some days in the week or parents with a particular aptitude for this work would be more likely to respond than others. Responsibilities, to be shared between as many parents or members of the children's families as possible, could include finding a suitable place to run the group, ensuring that the children come or are brought and that each parent understands what is being done and how the "lessons" are to be followed up at home.

As capacity-building for individual parents proceeds and as their confidence grows, some could take on the responsibility of conducting activities for some of the children in the group. For example, a mother who has successfully taught her child to count, or button a shirt, could sit with a few children in the group who need to learn these skills, and teach them as well as demonstrate the steps involved to other parents. Our role could be expected to become more and more that of resource persons, rather than primary implementers.

C. Facilitating collective ownership

Conscious efforts need to be made to design activities where parents can participate and contribute on an equal footing with us - if possible, more than us. For instance, groups of parents in a particular village could go and talk to the headmaster of the local school to persuade him to allow group activities to be conducted in the school. Parents could also use their more intimate and practical knowledge of local power structures to influence local schools to admit children with disability, wherever the nature of the disability makes this possible.

Disabled children parents' could form a consumer group to ensure equal access to service for their children.

D. Facilitate parent group building

So far, as efforts at group building have consisted of providing the space and opportunity for parents to meet and share their experiences. In some cases, meetings organised by us for large groups have been followed up by the parents themselves, who have met subsequently in smaller groups for social interactions.

However, experience has shown that more intensive efforts and active facilitation are required before these informal groups can become platforms for mutual counselling and sharing of



resources, as well as vehicles for collective action. Experience-sharing alone is not a sufficient basis for a group to come together and continue to work together - a long-term identity for the group grows out of certain well-defined common objectives. As facilitators of parent group formation, we need to identify these issues. Groups would have to be local. Our role as facilitators of the process would involve understanding the dynamics of interactions in the group, and helping to resolve issues of inclusion and leadership. We would also be instrumental in setting the culture and climate of the group, and establishing norms of mutual respect and a feeling of unity. The experience that we have with groups as vehicles for learning would have to be reassessed and built on in the specific contexts of disability and deprivation. Rather than maintaining an identity as experts or professionals, we should move towards a situation where we can bring the parents and families of children with disability together, with the understanding that if they could plan what they wanted to do for the children, we would help them to do it. The group could initially take up activities which have a high possibility of success, and would therefore serve to strengthen it. Since economic self-reliance for their children

is a major issue for most parents, this could be taken up and a step-by-step action plan prepared, to identify possible activities and sources of employment, assign responsibility to some members to explore each option in detail and to take specific action in the case of individual children. Formation of credit groups, and linking up with existing income-generating groups, are options we need to explore.

This shift in focus from individual to collective and group-based strategies has several implications for us.

1. Our present activities and structures have been evolved to match our focus on individuals. This structure may not have the capacity to handle the demands of a dual strategy. We may have to consider division of responsibilities, with some of us spending more time on individual "package" programmes, while others would concentrate on group-building. On the other hand, the fact that a close and deep relationship with the family is an essential requisite for group-building, must be kept in mind. In this sense, the person closest to the child would also be the most appropriate group facilitator.
2. Our skills in working to form and sustain groups are limited. We would have to take up an intensive capacity-building exercise for ourselves, including meeting and sharing others who have relevant experience in building issue-based groups. Our realisation that it takes more than a common agenda to sustain a group, also means that we have to learn how to initiate, facilitate and monitor the subsequent process of resolving group issues until a concrete plan of action is decided on and responsibilities shared out among members.
3. We would have to start functioning as a resource centre for parents' groups. We already have some experience,

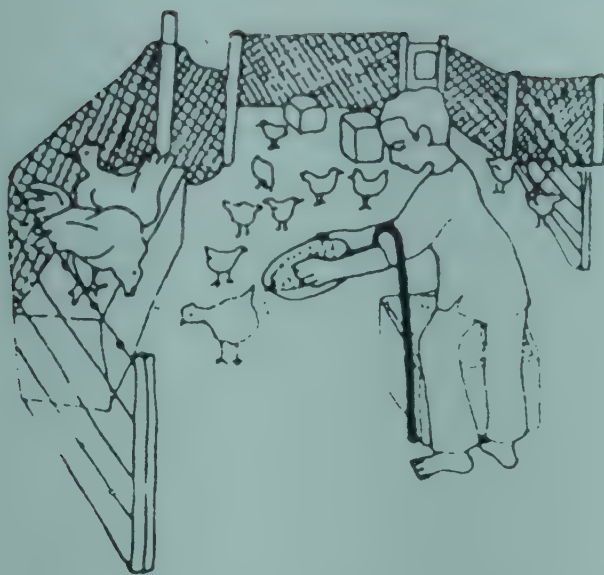
through our support programme, of functioning as a resource group for other disability workers and groups. The information base we already have would have to be expanded and processed to make it relevant, useful and accessible to parents.

4. We would have to think about increasing the size of the group. As the organisation has grown, so have the demands of our personal lives. It is no longer possible for each of us to fill multiple roles as well as successfully handle the emotional stresses and strains attendant on working with disability on a day-to-day basis. Sharing out our workload, to give each of us more space and time to unwind, would be possible with a larger team.

Change processes at the community level

Over the last five years of work, we have been able to build and sustain relationships with children with disability and those persons and groups closely connected with them - parents, families, neighbours and friends. Our relationship with other groups in the community is much weaker. In many cases, everybody in the village recognises us and has a vague idea of what we do, without being sure of the details. With certain specific groups in some villages - the Mahila Mandal, the school teachers or health workers - our relationship is somewhat deeper. However, when examined in the context of the desired change in the attitude of the community towards its members who are disabled, the need for specific strategies becomes obvious. This desired attitude could be summed up as one derived from an enhanced understanding of disability issues at various levels, expressed in changed attitudes and behaviour with respect to persons with disability.

1. Making persons with disability visible as persons in the community. Some strategies we have tried include creating opportunities for 'visitors' from other families to see children



with disability learning, working and playing together, by having learning groups work in central or common places in the village rather than in an individual's home. Children with disability could also, as part of their learning agenda, be taught some 'displayable' skills, such as singing or dancing. The children in a particular group could then put up a performance for the other families in the village. Seeing these children expressing themselves creatively can be a moving and unforgettable experience, and can establish them as individuals. This can be the basis of a continuing interest in them on the part of the rest of the community. Putting up such a performance can be an activity to be taken up by a parents' group. Since the chances of success are high, it will build solidarity and a sense of identity and confidence among both parents and children, as well as provide a basis for future interactions between the group and the larger community.

2. Using existing community-level groups as nuclei for change. Our earlier experience with existing NGO--sponsored women's

groups in the villages where we work indicates that it is difficult to persuade these groups to move away from their service orientation. However, there are a number of other community-level groups where the possibility of introducing disability as a part of the agenda can be actively explored. One such resource is the Youth Club which exists in every village. Activities which do not require sustained involvement or expenditure of money may be used to create interest and involvement in these groups. For instance, the members of the club could get together and contribute a day's work to repair a path in the village to make it usable by a child in a wheelchair, or help to build a stage for a performance by the children. It is important to remember that the initiative for involving these clubs must be taken by parents' groups and not by us, since we (and other NGO's working in the area) are generally identified as potential employers rather than as facilitators of community initiatives.

3. Establishing contact with local administrative and panchayat structure. Here again, the initiative would have to come from parents' groups, perhaps around issues of available benefits under government schemes for persons with disability.

Our experience of organising a camp for the distribution of certificates to persons with disability in the two Blocks where we work has given us an idea of the complex dynamics involved in liaising between various government departments, the panchayats and persons with disability and their families. The process involved each person obtaining a certificate from the local panchayat to the effect that the person was a resident of that particular village, getting the person examined and assessed by a team from the District Hospital and an identity card being issued on the basis of this assessment by the local Block Development Officer (BDO). Even though we, and not the families, were the prime movers in the process, the camp gave

families an experience of collective actions and identity. Possibilities for taking this feeling ahead and making it a basis for acting for change, can be explored. For instance, the initial motivation for obtaining an identity card for each child was the fact that these cards could be used for free travel on public transport. The day after the camp, however, we were notified that this free travel facility would no longer be available on privately-owned buses. Since these are the commonest form of transport in our area (government buses being few and far between), that notification has made the cards practically useless. Parents' groups could now use their visibility and identity at the Block level by initiating action to get the facility renewed. Groups could liase with panchayats and political party units to raise this demand at the Block level, and keep up the pressure to have it taken up at the district level with an order to transport operators. This experience of collective action would, if successful, increase the confidence and solidarity of the group and make it possible to plan for further collective action.

4. Using all possible occasions to raise the issue of disability. Occasions such as meetings of village-level groups and community gatherings or school functions can become opportunities where people can reassess their impressions about children with disability. Successful experiences can be publicised and shared by the parents concerned or by parents' groups. These experiences may become the basis for recognition of the possible potential of other children with disability.
5. Using the child-to-child approach to introduce children with disability into local schools. In many cases, local teachers do not oppose the idea of admitting these children to the school, but are apprehensive about being able to provide the special care and teaching which may be required. The possibility of the child with disability being introduced to the class and



looked after by an older child from the same locality with whom a relationship has been built up, is one way of demonstrating to teachers that these children do not present insurmountable special problems. Of course, this would not be possible in the case of children who have severe learning disabilities or problems in communicating. Many children with mild cerebral palsy fall into the category for whom this approach

may be useful. Our support, in the form of special remedial teaching for the child, would also be essential.

Networking and support to other groups

When we started our support programme, it was with the idea that we could put our field experience to use in capacity-building for disability workers from other organisations. Our experience with this programme so far indicates that a partnership with another organisation involves a far more intensive relationship. The philosophy and style of functioning of the other organisation affects our interaction. We are increasingly finding that our partnership in designing and implementing a people-centred disability rehabilitation approach leads to a reassessment of overall organisational strategies and structures, which we are expected to facilitate. In the process, we are clarifying our ideas about the links between disability and development.

Our initial idea, that we would work only with organisations who already have a working network of community-level groups, is, we have found, not necessarily a formula for success. Our experience in building groups around the issue of disability has increased our confidence in trying to tailor our support to the needs of the

organisation and the reality on the ground. Instead of being restricted to training of workers, our focus will be on building a common platform with groups we support.

As we interact with more and more organisations, we are coming to realise that 'being 'purists', in the sense of avoiding interactions with institutions who do not seem to share our philosophy of people-centred development, is a hinderance to our objective of effective advocacy. There is often a gap between the philosophy of the organisation as stated, and as practiced, which further complicates the situation on the ground. To understand all the implications of these dynamics in the context of disability, is possible only through intensive interactions. We are now taking every opportunity to interact with other organisations and initiate dialogues on our basic understanding of the work we are each doing, while trying to be sensitive to the specific situation as it exists as well as ourselves being receptive to learning and change as a result of the exchange.



This is the first time, since we started working, that we have attempted to define and articulate our collective vision, philosophy and strategy. We started this process by analysing our experience, and most of our strategies are built from this. However, the process of articulation itself has helped to take us forward to a new level of conceptual understanding. Thus, some of our proposed strategies are hypotheses which still need to be tested in the field.

Our primary strategic focus in the coming years will be on collective approaches. In arriving at this understanding, we have used our own experience of working as a group, and analysed the advantages, constraints and dynamics of our own collective. It is this analysis which we now propose to use as a basic framework for implementing this approach in the field. The process of learning will continue as we acquire and assimilate actual experience of forming, sustaining and working with groups.

Chapter - VI

CONCLUSIONS

The process of reflecting on and analysing our work, of which this document is the outcome has been going on over the last year. We have shared our discussions, and preliminary drafts of our writings, with many of our friends. Some have commented on the fact that many of the experiences we had documented seemed to be "negative". Over these years, we have also had experiences which are "success stories" and very obviously "positive". These have also been sources of inspiration and strength, but, looking back, we could see clearly how working with some of our children has helped take forward our understanding of deeper issues, our respect for the people who are our partners, our sensitivity to the realities of their situations and our own growth as human beings. It is these experiences we have chosen to highlight.

We have also been asked "Do these people always see their children as a burden ? Don't they love them ?" We have learnt that there are many ways of showing love and expressing concern, and we have learnt to recognise and respect them all. It is a constant source of joy and wonder that, in spite of the conditions in which these children live, there is so much love in their lives.

Another point we would like to emphasise is that all the members of our collective belong to the middle-class, with all the attitudes and biases which this background has given us. Although we have tried consciously to break out of these in our work and in analysing it, there may be places in this document where a word or phrase we have chosen to use or our way of presenting an issue, reflects these biases and attitudes.

Many of our friends have asked us about the "replicability" of our "model". Our experiences have taught us that there are no fixed rules and models in working with people. In our advocacy of a community-based approach, we share our basic belief that people, their

communities, problems and solutions are different everywhere, and approaches to development must be flexible to meet and match people's needs.

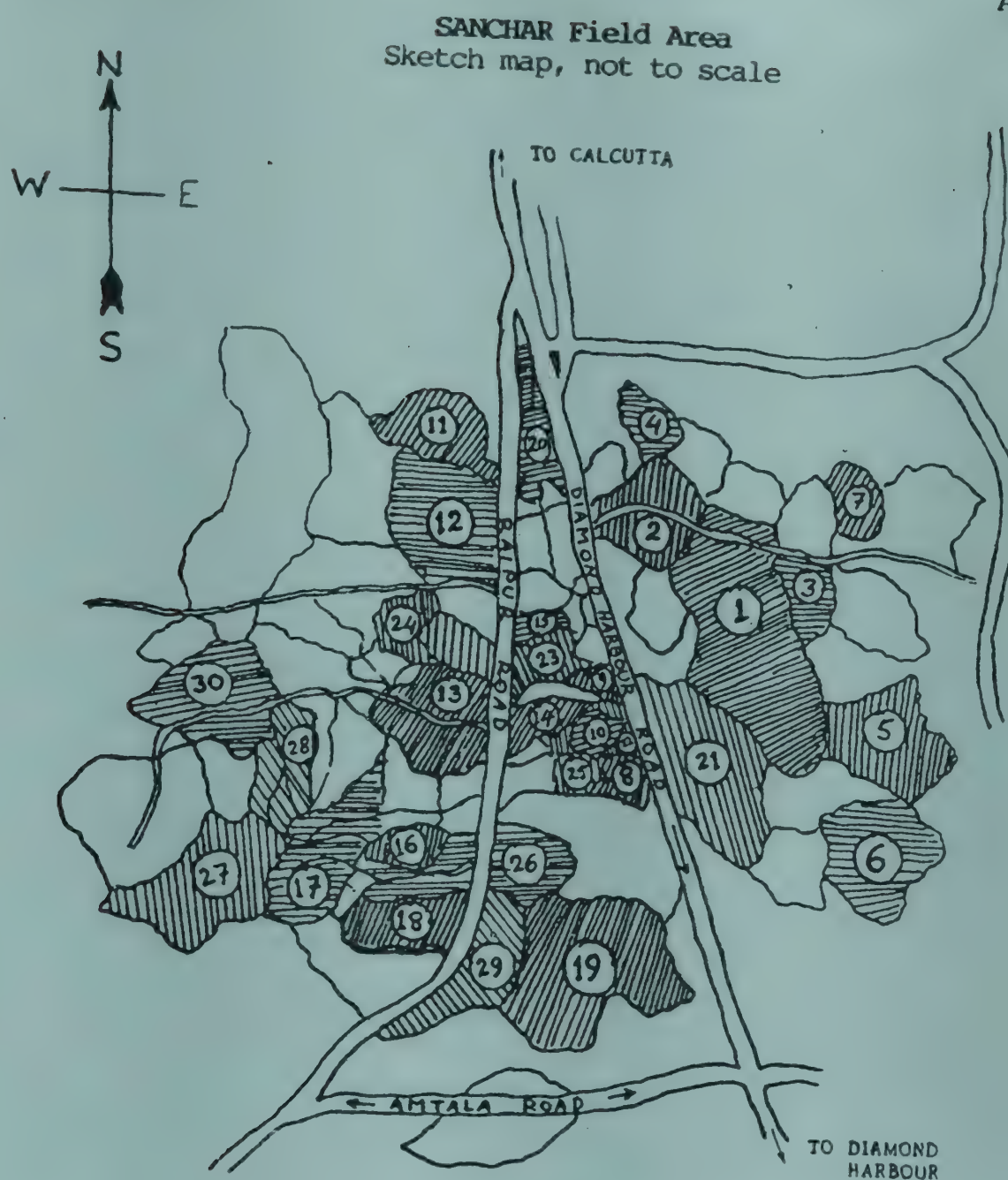
In trying to look at disability holistically, as a "development" issue, we feel that the following are essential :

- Sensitivity to people's own understanding of the issue.
- Respect for the person with disability, as another human being.
- Creating opportunities for people with disability to become equal members of their communities.

Although our understanding of the links between disability and development has deepened, we have not come to the end of our learning growth. This process of working, looking at and learning from our experience, and going back to work with a new understanding, will continue.



Appendix



Code	Village	Block
1.	Angachia	Bishnupur I
2.	Daulatpur	Bishnupur I
3.	Krishnarampur	Bishnupur I
4.	Rajarampur	Bishnupur I
5.	Kastomahal	Bishnupur I
6.	Abjakhali	Bishnupur I
7.	Jhanjra	Bishnupur I
8.	Kajirhat	Bishnupur I
9.	Uttar Kajirhat	Bishnupur I
10.	Parbatipur	Bishnupur I
11.	Bonogram	Bishnupur II
12.	Raspunja	Bishnupur II
13.	Samali	Bishnupur II
14.	Bochberia	Bishnupur II
15.	Nawbad	Bishnupur II
16.	Samukpota	Bishnupur II
17.	Angarberia	Bishnupur II
18.	Nandabhanya	Bishnupur II
19.	Borogegangoalia	Bishnupur II
20.	Hanspukur	Metiabruj
21.	Khoriberia	Bishnupur I
22.	Bhasa	Bishnupur I
23.	Powalia	Bishnupur II
24.	Halderpukur	Bishnupur II
25.	Chandipur	Bishnupur II
26.	Gazipur	Bishnupur II
27.	Mukundapur	Bishnupur II
28.	Ramnagar	Bishnupur II
29.	Kangonberia	Bishnupur II
30.	Purasar	Bishnupur II

DEMOGRAPHIC DATA FOR VILLAGES IN FIELD AREA

(Source : Census 1991)

Sl. Name of Village	Population			Children (0-6 years)		% Literacy	
	Women	Men	Total	M	F	Women	Men
1. KRISHNARAMPUR	217	220	437	57	60	22.1	55.9
2. AMGACHIA	3230	3625	6855	753	737	30.4	56.4
3. KASTAMAHAL	2673	2801	5474	526	439	26.6	52.2
4. DAULATPUR	1987	2199	4186	404	379	31.2	52.3
5. RAJARAMPUR	550	579	1129	89	95	51.5	68.9
6. KAJIRHAT	664	708	1372	134	125	39.2	56.8
7. ABJAKHALI	946	980	1926	184	202	25.2	56.8
8. UTTAR KAJIRHAT	945	967	1912	152	158	43.7	68.3
9. PARBATIPUR	622	662	1284	117	121	35.0	61.5
10. JHANJRA	281	305	586	38	42	33.1	51.2
11. NANDABHANGA	2248	2361	4609	406	393	41.5	62.0
12. RAIPUR	594	697	1291	NA	NA	20.5	36.9
13. ANGARBERIA	1103	1123	2226	NA	NA	41.4	71.9
14. NAUHAZARI (BONCHBERIA PARASAR)	5671	5916	11587	1311	1266	20.5	40.5
15. BANAGRAM	1370	1491	2861	NA	NA	22.9	48.4
16. NAWBAD	962	1113	2075	NA	NA	33.9	55.2
17. SAMALI	1970	2128	4098	NA	NA	27.9	48.2
18. RASPUNJA	3077	3344	6421	569	494	33.2	54.4
19. BARAGAGANGOALIA	2210	2280	4490	291	280	53.6	72.4
20. HANSPUKUR	NA	NA	1500	NA	NA	NA	NA
21. KHARIBERIA	850	904	1754	NA	NA	40.7	54.6
22. BHASA	699	775	1474	NA	NA	33.4	51.3
23. POWALIA	NA	NA	NA	NA	NA	NA	NA
24. HALDERPUKUR	NA	NA	NA	NA	NA	NA	NA
25. CHANDPUR	660	677	1337	NA	NA	39.6	57.3
26. GAZIPUR	1256	1287	2543	NA	NA	30.7	55.3
27. MUKUNDAPUR	233	241	474	NA	NA	23.6	44.8
28. RAMNAGAR	702	802	1504	139	122	21.5	60.7
29. KANGONBERIA	2862	2911	5773	386	413	43.7	65.5
	38582	41096	81178			32.09	54.06

Note :

1. Villages mentioned in Census date as Revenue units.
2. Population figures for Nauhazari include 9 villages of which we work in two.
3. NA : not available.

